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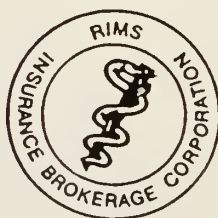
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Learning Impairment in Childhood

The purpose of bringing together research studies on preventing risk of learning impairment is to sound an alarm for state and federal policy makers in education, health, and the environment. There are known health, environmental and poverty-based hazards in our midst that are compromising the ability of children to learn as well as their natural endowment would allow. And much of this learning impairment is preventable through enlightened policy-making and programs attentive to the particular vulnerability of children and their families.

Perspectives underlying the approaches presented in this issue are complex. They include recognition that a child's development cannot be viewed separate from the context of caretakers, influential environmental factors, or the surrounding social and cultural milieu into which the infant is born. In addition, it is necessary to integrate research from many fields that use different methodologies and different forms of

measurement and analysis. In our synthesis of the studies, we have attempted to differentiate between cause and association, between those factors that are known to have a direct relationship to learning loss and those whose relationship appears indirect.

"Preventing Risks of Learning Impairment," by Newman and Buka, synthesizes from a national perspective, an overview of exposure of young children to preventable risks, and "Lead Poisoning" by Simon and Zimmerman describes lead as an environmental hazard in Rhode Island.

Perspectives on prevention are presented by three other articles. "Perinatal Care and Learning Disorders: A Community View," by Culpepper, Jack, Hunt, McGuire, and Mattis, describes a community-based program for improved perinatal services in the Blackstone Valley of Rhode Island. Kochanek in "The Role of the Physician in Early Intervention Screening for Infants and Toddlers," demon-

strates the effectiveness of very early intervention with children at risk. "Traditions and Innovations: A Community-Based Approach to Substance Abuse Prevention" by Parker, Thomas, and Comacho, describes a drug and alcohol abuse prevention program with Native American high school students in Rhode Island.

Lucile F. Newman, PhD

Aging 2000: A Rhode Island Community Effort

Few people know how to grow old; aging is an art not willingly learned in childhood or maturity. Aging is thrust upon most of us ill-prepared to appreciate its needs, or anticipate its graceless discomforts. If adulthood is a struggle, then old age is often a regrettable interval of despair.

We may judge a society by the earnestness of its efforts to care for its frail elderly. And, despite immense investments of money

and resources, even the most naive amongst us will concede that we nurture our elderly both indifferently and inadequately. Certainly with the professional skills, administrative talent and moral purpose in Rhode Island, a better way of doing things can be envisaged.

In the last year a committee of 150, under the active leadership of Ira C. Magaziner, has asked the simple but fundamental question: Given a blank sheet of paper, and disregarding current restrictions, how would you design an ideal system for elderly care?

Aided by a staff of ten professionals, these 150 volunteers, (including many physicians and health professionals), have begun a determined inquiry into the current ways we administer our clinics, hospitals and nursing homes. How do we spend our moneys, and yet somehow contrive all of the bureaucratic duplications and contradictions of elder service? Why do we communicate ineffectively, and manage our institutions with insensitivity and inefficiency? And from the litter of these painful studies, an attempt is now being made to retrieve pieces of the system which merit preservation, to which can be added components, designed by others or not yet devised, ultimately to assemble a comprehensive system of care for frail elderly in this state.

This issue of the *Journal* carries an introductory commentary on Aging 2000 written by Magaziner. Subsequent issues shall carry summaries of the following working papers:

- Easing access to the elder care system
- The "Social HMO" as a total

care package

- The elder care advocate as a total care coordinator
- Single source alternatives to elderly care funding
- Community-based centers for home care services
- Creating ethical protocols to inform the design, implementation and decision-making of the care system
- Affordable continuum of care options: an alternative to institutions?

- Organizing education and training programs for providers, consumers and the general public

- A strategic look at the costs of the elderly care system

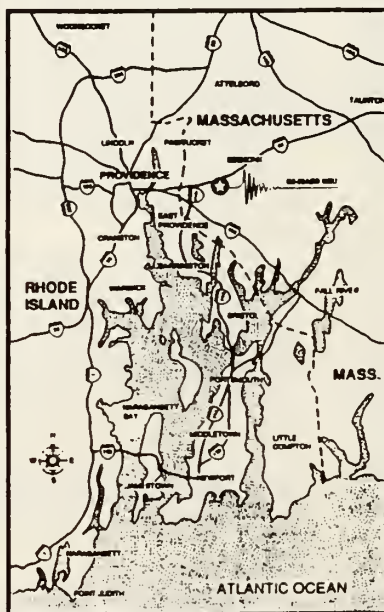
The *Journal* welcomes active, critical participation and commentary from its readers on these evolving articles.

Stanley M. Aronson, MD

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Preventing the Risk Factors in Childhood Learning Impairment

Lucile F. Newman, PhD
Steven L. Buka, ScD

The study . . . includes only those children who are in the normal range of intelligence, but whose learning and eventual capacities have been so compromised that they are at risk for school failure.

"Learning Readiness" was one of the key national goals of the Education Summit of 1989, and yet it is known that many children arrive at school with impaired learning capacity. The Preventing Risks of Learning Impairment Project has synthesized research from many current sources to identify major preventable conditions associated with an increased risk of these learning problems. Their unexpected prevalence and severity suggested the need for attention to prevention. The study does not include mortality or retardation. It includes only those children who are in the normal range of intelligence,

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but whose learning and eventual capacities have been so compromised that they are at risk for school failure. This report will first identify the most pervasive risk factors, and then consider some successful strategies for prevention.

Conditions of Risk

The most preventable conditions that put infants and children at risk are, in infancy, low birth weight, prenatal exposure to legal drugs, such as alcohol and nicotine, and prenatal exposure to illicit drugs. In childhood, the most threatening factors are exposure to lead, child abuse and neglect, and malnutrition. The resulting learning problems range from delayed speech to cognitive and attentional deficit disorders and hyperactivity to lowered IQ. These are characteristics that without intervention, can lead to poor school performance.

For all of the conditions, poverty, social disadvantage, or parental disinterest are major contributing factors. School age

pregnancy continues to contribute to preterm birth, and to increase the number of single parent families. Lack of adequate health insurance and child care make prenatal care beyond the reach of many poor women, also contributing to prematurity and infant morbidity. However, not all children with learning disorders or suffering from these conditions come from disadvantaged families.

ABBREVIATIONS USED:

FAS: Fetal Alcohol Syndrome

IQ: Intelligence Quotient

IUGR: Intrauterine growth retardation

LBW: Low birth weight

LD: Learning deficiency

NHANES: National Health and Nutrition Examination Survey

UCLA: University of California, Los Angeles

WIC: Women, Infants and Children

The impact on learning of each of these risk conditions is difficult to measure because they are often intertwined. For example, low birth weight is an outcome of many of the factors described here, such as smoking, cocaine and "crack," alcohol, prenatal lead exposure, or maternal malnutrition. Estimating the prevalence is complex also because the same child may be subject to multiple conditions, adding to the severity of the learning problems. Schools in poverty neighborhoods see much higher percentages of their children affected. And the risk factors have different effects depending on the intensity of exposure and at what point in the child's development they take place.

In addition, not every exposure results in impairment. Some children are more resistant and resilient than others. High risk exists when a child has a greater than average chance of developing a disability. Risk, therefore, is not a certainty of impairment, but a set of circumstances in which there is an increased probability that a disorder will occur.¹ Not every exposure results in measurable damage. What is clear, however, is that failure to address these preventable risk factors adds an enormous burden to the nation, the schools, and to the lives of these children and their families.

Increasingly specialized and narrowly focused scientific studies have worked to isolate and thus better define each subject. This has resulted in separation of the analysis of risk factors at a time when an important issue is their additive or cumulative impact. Therefore, a synthesis of these disparate lit-

eratures is required to achieve an understanding of the major factors in learning limitation, to estimate their interaction with poverty and disadvantage, and to identify possible strategies for prevention or amelioration. For each we asked the following questions: 1) what is the prevalence of the risk factor; 2) how does it affect the child; 3) how many children are affected; and 4) what have been strategies of effective intervention.

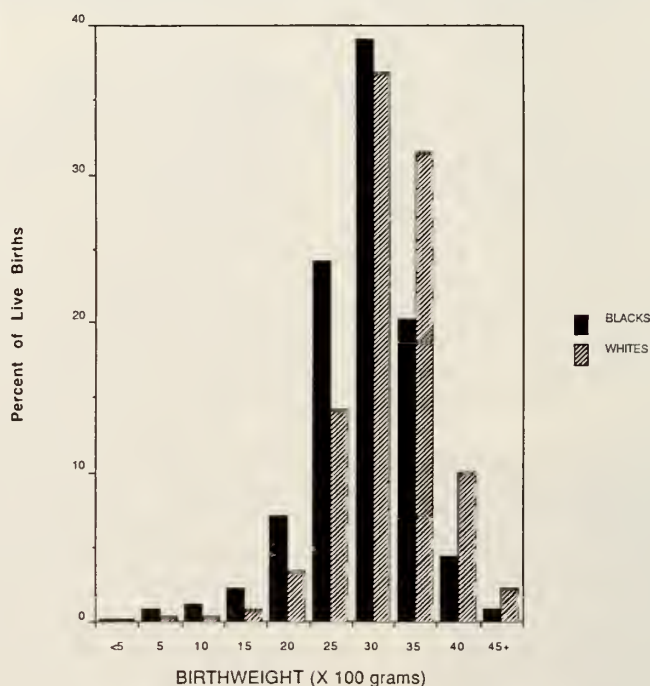
Low Birthweight

About 6.9% of infants in the United States are born under 2500g. In 1987, this accounted for some 269,100 infants. Low birth weight may result from preterm birth at an early gestational age, or it may be caused by intrauterine growth retardation (IUGR) resulting from placental insufficiency, maternal

malnutrition, or actions that restrict blood flow to the fetus, such as smoking or cocaine use. Very low birth weight infants are those born below 1500g and extremely low birth weight refers to those under 1000g at birth. Figure 1 indicates the distribution of live births by birth weight in 1980. While black infants are born at slightly lower weights than white, their predominance at the very lowest levels indicates that they are more than twice as likely to be born at very low birth weight.

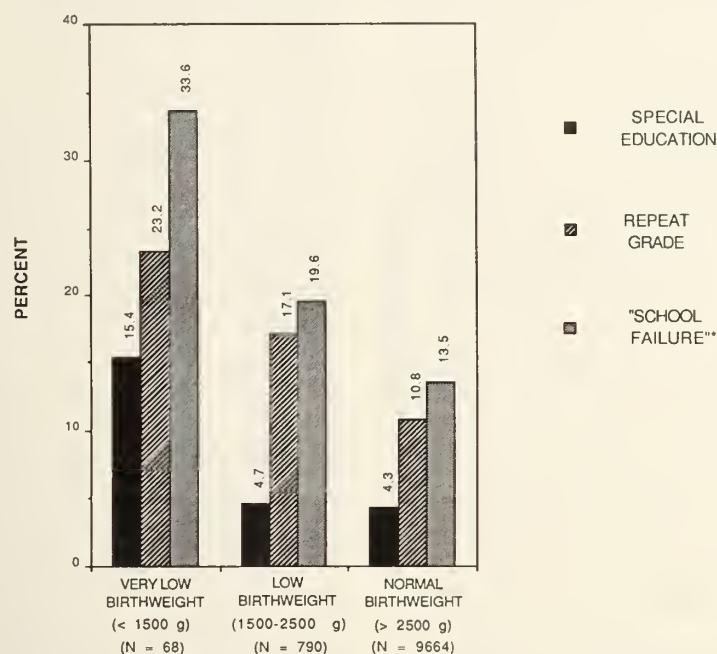
Figures 2 and 3 demonstrate two views of the relation of birth weight to learning. Figure 2 relates birth weight to various measures of learning impairment including repeating grade, assignment to special education classes, or the overall designation of "school failure".² Figure 3 is based on intelligence and

Figure 1. Distribution of Live Births by Birthweight and Race, 1980



From: MMWR, March 1990

Figure 2. Relation of Birthweight to Various Measures of "School Failure" among children Aged 4-17

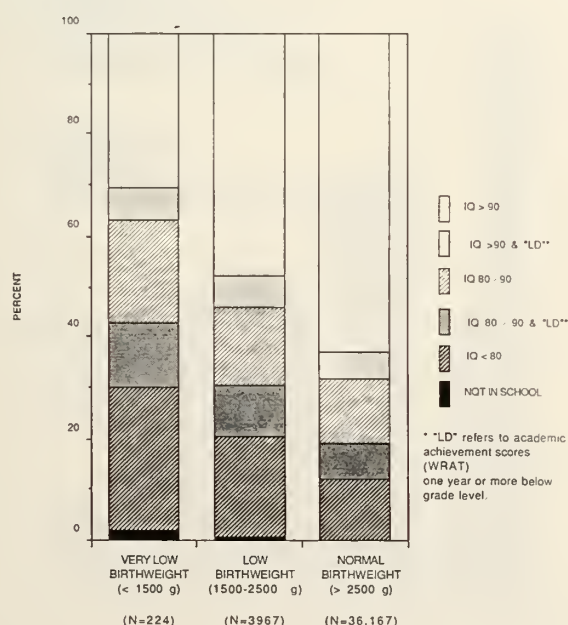


academic achievement scores. The "LD" (learning deficiency) refers to academic achievement scores one year below age. Both figures demonstrate a striking increase of impairment with decreasing birth weights.

New technologies and the regionalization of neonatal intensive care have, over the past decade, resulted in improving survival rates of infants born at a birth weight of 1500g - 2500g. As Figure 2 shows, however, those born at low birth weight are at increased risk of school failure. Even with advances in survival, very low birth weight infants below 1500g are at particularly high risk for visual and auditory impairment, and learning disorders including impaired language skills requiring remedial instruction.³⁻⁸

Over the five years from 1983 to 1987, 6.2% of infants in Rhode Island were born at low birth weight, or, under 2,500g., and 1.1% at very low birth weight, or, under 1,500g.

Figure 3. Relation of Birthweight to Intelligence and Achievement Scores at Age Seven



FROM: Buka SL, et al., 1990. Based on 40,000 children followed from birth (1960-1966) to age seven in the National Collaborative Perinatal Project.

Over the five years from 1983 to 1987, 6.2% of infants in Rhode Island were born at low birth weight, or, under 2500g, and 1.1% at very low birth weight, or, under 1500g.⁹ Changes, however, are taking place due to aggressive management of extremely low birth weight infants in intensive care. Vohr (1990) notes an increasing survival rate of infants under 1000g with a "decreasing prevalence of major disabilities, and increasing identification of developmental abnormalities" (p.233). Implications of these changes are to intensify the need for long-term follow-up, early identification of

developmental problems, and continued diagnostic evaluation to school age.¹⁰

Risks to these infants are not only physical. Observations of parent-infant interaction in neonatal intensive care suggested that many parents distance themselves from an infant that appears to be nonviable.¹¹ In a study of 126 preterm infants under 1500g, Sigman *et al* found that postnatal complications alone did not predict developmental outcomes at 25 months.¹² In a review of follow-up studies of low birth weight infants at school age, Aylward *et al* concluded "the influence of the environment far outweighs most effects of non-optimal prenatal or perinatal factors on outcome."¹³

Maternal Smoking

Maternal smoking during pregnancy has long been known to be related to low birth weight, intrauterine growth retardation, and long term growth reduction,¹⁴ as well as to an increased cancer risk in offspring.¹⁵ One of the earliest postnatal effects noted by researchers was that maternal smoking is associated with early and persistent asthma, causing, among other problems, frequent hospitalization and loss of time in school.¹⁶

A growing number of new studies have shown consistent deficits among children of smokers in stature, in cognitive development, and in educational achievement. Relationships between maternal smoking and problems in cognitive function and school achievement, however, are complex. It is not clear that smoking in itself is the cause of the problems, but it is clear that smoking is associated with later learning problems. To give

a sense of how different factors work together, smoking is related to IUGR because one mode of effect is constriction of placental blood flow. In addition, it is difficult in assessing the respiratory effect of smoking on childhood asthma, to differentiate between prenatal exposure and post birth passive exposure to smoke from either parent. Figure 4 indicates the percent of women of child-bearing age smoking by age group in 1985. Women from 18-24 are the only group increasing smoking. Figure 5 shows the percent of children with various indications of learning impairment by the number of packs of cigarettes a day smoked during pregnancy.

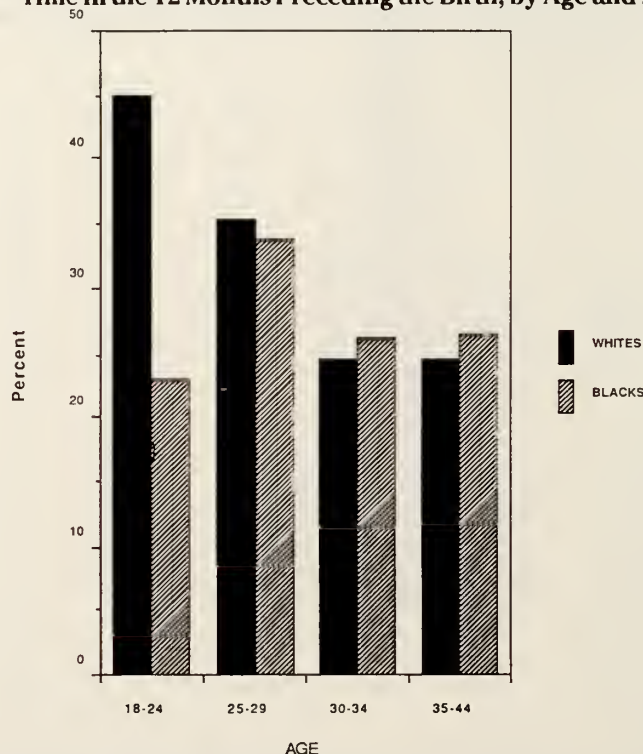
Maternal Alcohol Use During Pregnancy

Around 40,000 infants per year are born with alcohol-related

problems as a consequence of maternal alcohol abuse during pregnancy. The numbers affected are lower than the other risk factors described, but the effects are significant. In 1984, an estimated 7,000 of these infants were diagnosed as having fetal alcohol syndrome (FAS), a condition so severe as to place them in the category of major retardation and therefore beyond the scope of this study. There are, in addition, about 33,000 children each year who suffer from less severe alcohol-related impairments. The more prominent among these are attention deficit disorders, hyperactivity, and speech-language pathologies. General school failure is often connected with a history of fetal alcohol exposure.^{17,18}

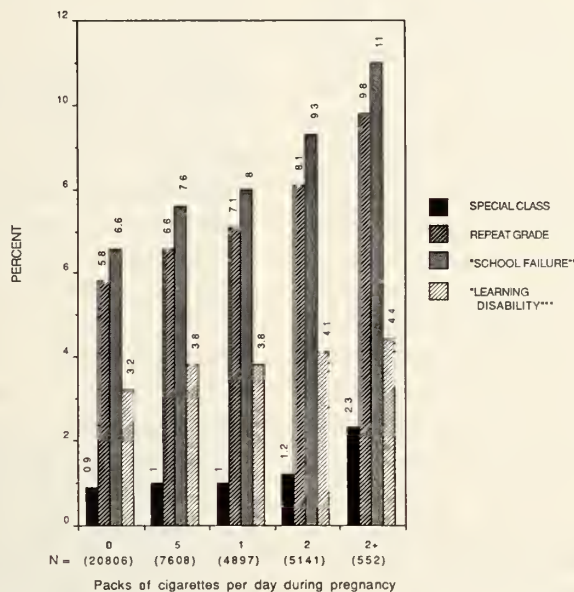
Figure 6 shows two indications of the extent of alcohol use

Figure 4. Percent of Women Who Had Given Birth to a Child Within the Past 5 Years who Reported Having Smoked Cigarettes at any Time in the 12 Months Preceding the Birth, by Age and Race, 1985



From: US Department of Health and Human Services, 1988.

Figure 5. Relation of Maternal Cigarette Smoking During Pregnancy and Various Measures of "School Failure" and "Learning Disability" at age Seven



FROM: Buka, SL, et al., 1990. Based on 40,000 pregnancies followed to age seven in the National Collaborative Perinatal Project.

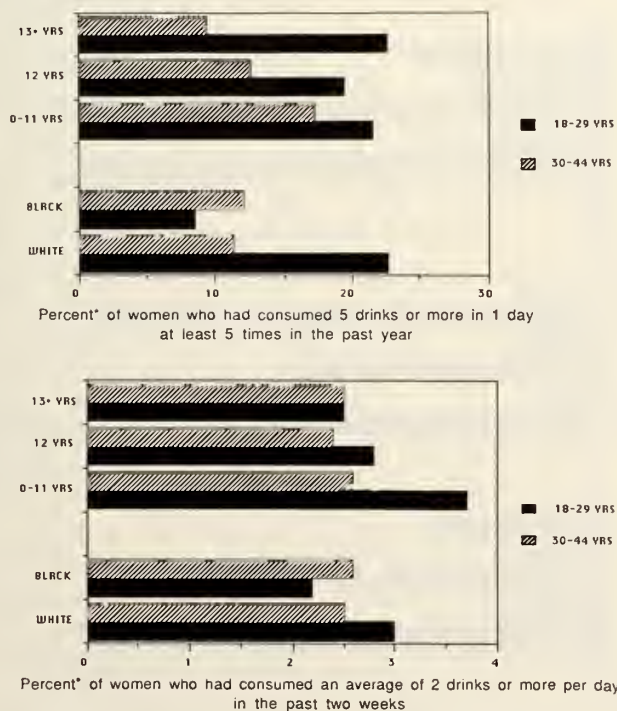
* "School Failure" = Repeat Grade or Enrolled in Special Class

** "Learning Disability" = Normal intelligence (IQ>90) and Reading or Spelling Scores one year or more below grade level.

among women of reproductive age, 18-29 and 30-44, by race and educational achievement. The percent of white women 18-29 reporting "binge" drinking (defined as five drinks or more a day at least five times in the past year) is consistently higher (around 23%) than black women of the same age. Steady alcohol use (defined as an average of two drinks or more per day in the past two weeks) occurs at a lower rate, around 3% for both black and white women.

In 1984, an estimated 7,000 ... infants were diagnosed as having fetal alcohol syndrome, a condition so severe as to place them in the category of major retardation and therefore beyond the scope of this study.

Figure 6. Drinking Habits of Women Aged 18-44, by Age, Race and Education Level, 1985



From US Department of Health and Human Services, 1988.

* Note different scales

The alcohol consumed by a pregnant woman easily crosses the placenta, but the mechanisms by which it affects the fetus is not well known. The most likely are a lack of oxygen to the fetus, abnormal muscle development, and changes in hormone metabolism. Thiamin deficiency in heavy drinkers, associated with brain damage in infants, may result from a number of additive causes.¹⁹ Many of the effects are not apparent until age 5 to 7, on entering school.

The effects of alcohol function differently at different points in development, indicating that there are critical periods of fetal growth when the developing organism is particularly subject to toxic substances. The first trimester of pregnancy is a period of brain growth and organ and limb formation. The embryo is most susceptible to alcohol from week 2 to week 8 of devel-

opment, a point at which a woman may not know that she is pregnant.²⁰

Fetal Drug Exposure

The abuse of drugs of all kinds, including marijuana, cocaine, "crack," heroin or amphetamines, by pregnant women affects about 11% of newborns every year (375,000 in 1987).²¹ Figure 7 indicates lifetime use of marijuana and cocaine in women 22-44 years, by ethnic group and educational level as reported in a national study. As with alcohol use, white women and those of the highest educational level report the greatest amount of use of cocaine at any time in their life at 16-19%. Marijuana use shows the same pattern at 49% lifetime use. Drug use during the past month follows similar trends. In a 1989 anonymous State Department of Health survey of all women delivering at Rhode Island hospitals, cocaine or its metabolites were indicated in 2.5% or 1 in 40 infants born in this state.²²

The abuse of drugs of all kinds, including marijuana, cocaine, "crack", heroin or amphetamines, by pregnant women affects about 11% of newborns every year.

Cocaine and crack use during pregnancy are consistently associated with lower gestational age, lower birth weight, and smaller head circumference in comparison with drug-free controls.²³⁻²⁷ As in alcohol use, drug use has different effects at different points in development. Very early use is more likely to cause birth defects affecting more basic endocrine, metabolic, central nervous system or

organ malformations. Later use may result in preterm birth and IUGR.²⁸⁻³⁰ While some of the symptoms may be immediately visible, some others may not be apparent until later childhood.^{21,31,32}

It is in the areas of behavioral and neurobehavioral development that previously unrecognized effects of prenatal drug exposure appear, particularly if careful developmental assessments are made. In infancy, these include problems in sleep-wake state regulation, and in childhood, visual orientation, motor control, and in interactive behaviors.²⁴ These may be caused

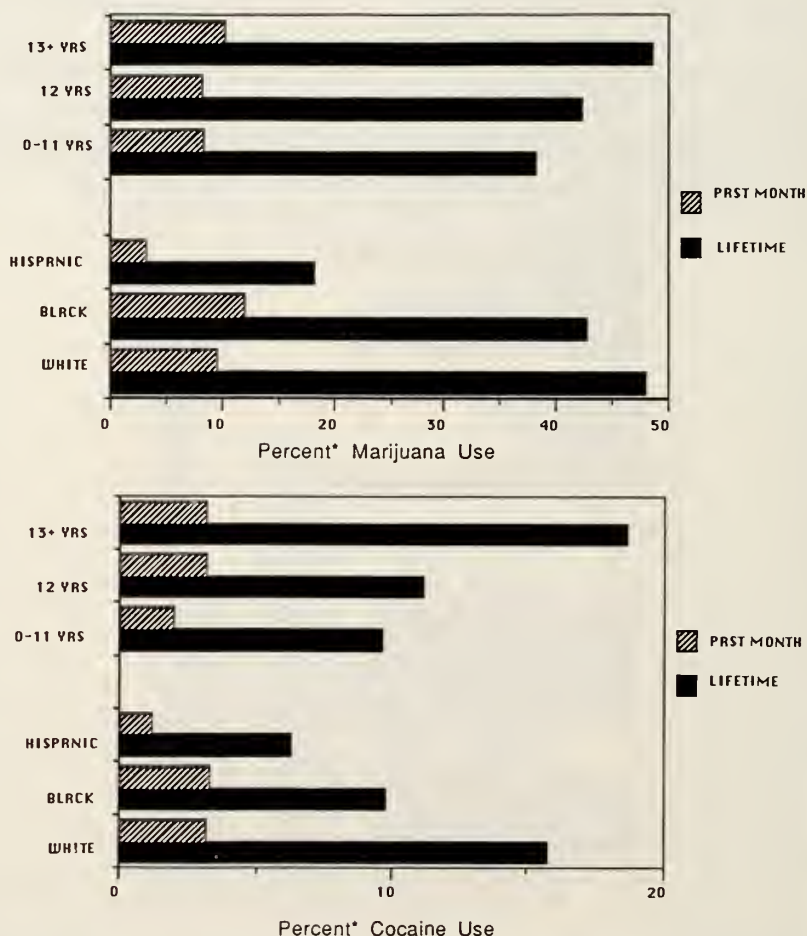
not only by drug exposure of the fetus, but also by insufficient prenatal care and a difficult environment for the infant at home.³³

Early intervention is especially important in programs to enhance cognitive and social abilities of these children. Neurobehavioral effects may be ameliorated by placing the child in a benign environment for day care at an early age.

Lead Poisoning

Lead is the most pervasive pediatric environmental hazard in the United States,³⁴ and one of the most expensive to remove.

Figure 7. Prevalence of Marijuana and Cocaine Use among Women Aged 22-44 Years, by Race and Education Level



From Adams, 1989. Based on 2,125 respondents to 1985 National Household Survey on Drug Abuse, NIDA.

* Note different scales

There is no use for lead in the human body, and its negative effects occur at many different levels from cell to structure. At a lead level above 40 $\mu\text{g}/\text{dl}$ (micrograms per deciliter of blood), injury may affect all body systems.³⁵ While the highest levels have declined with the decline of leaded gasoline, disturbed biochemical functions are discernible at even low concentrations.³⁶ Consistently, studies have shown that the highest levels in children still occur in inner cities.

Lead is the most pervasive pediatric environmental hazard in the United States, and one of the most expensive to remove.

In the past few years, researchers have concluded that smaller and smaller amounts of lead cause damage. Based on NHANES II data, the Agency for Toxic Substances and Disease Registry estimated that in 1984, 20,700 children 6 months to 5 years of age had blood lead levels greater than 25 $\mu\text{g}/\text{dl}$, and 2,380,600 (17% of preschool age children) were above 15 $\mu\text{g}/\text{dl}$.³⁷ Even at low blood levels of lead, various neurological and enzyme processes are impaired. Some central nervous system effects have been observed at levels below 15 $\mu\text{g}/\text{dl}$.³⁵ Even extremely low levels of lead can lead to lower intelligence of a child, to deficits in verbal and auditory processing and behavior disorders, to increased distractibility and daydreaming, to a lack of persistence and organization and to the inability to follow directions.^{38,39} A major follow-up study has shown that through age 18, early lead ex-

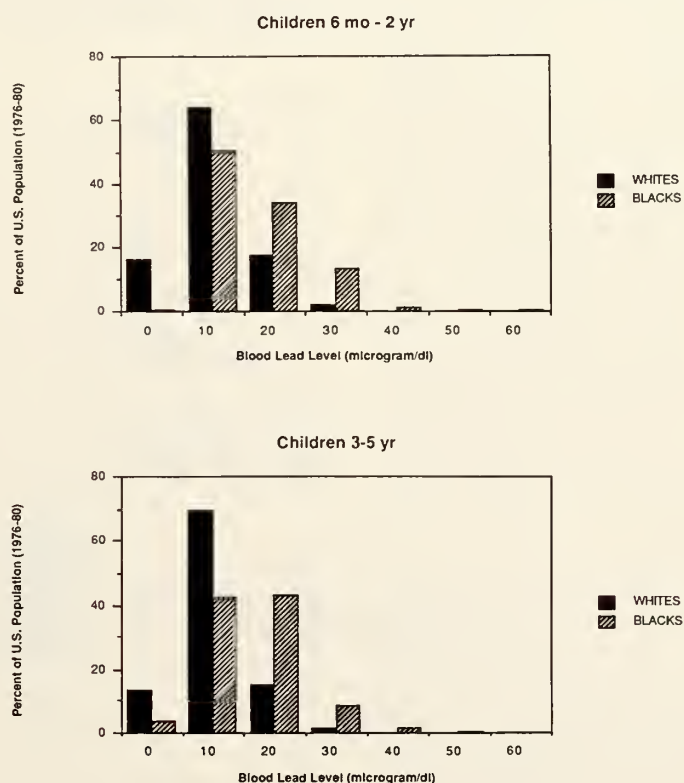
posure is associated with school failure and diminished cognitive functioning.⁴⁰

Sources of lead exposure include industrial contamination, leaded paint, leaded gasoline, ceramics, household dust and soil, lead soldered pipes, water, and tinned food. Lead does not degrade in the environment, but becomes dust, making it easier to ingest. Fetal or early postnatal exposure results in neurological delay or deficits, especially in situations of biological risk or social disadvantage. Children of all socio-economic and geographic groups are at risk, though urban environments with pre-World War II housing and residence near major roads or industrial sites provide more sources of lead exposure than

others. Of all environmental pollutants, lead is especially of concern in that the amount at which verifiable poisoning takes place differs very little from the amount found in most communities.³⁴

It is a silent condition without signs and symptoms until the level becomes extremely high, resulting in hospitalization. Primary prevention requires elimination of additional lead in the environment. Lead abatement programs, including soil and dust removal in high risk areas, exist in a few states. Secondary prevention requires mandatory screening to determine what lead level each child sustains and environmental or therapeutic interventions for those at greater risk.

Figure 8. Blood Lead Levels by Race and Age, 1976-1980



From: Mahaffey KR, et al., 1982.

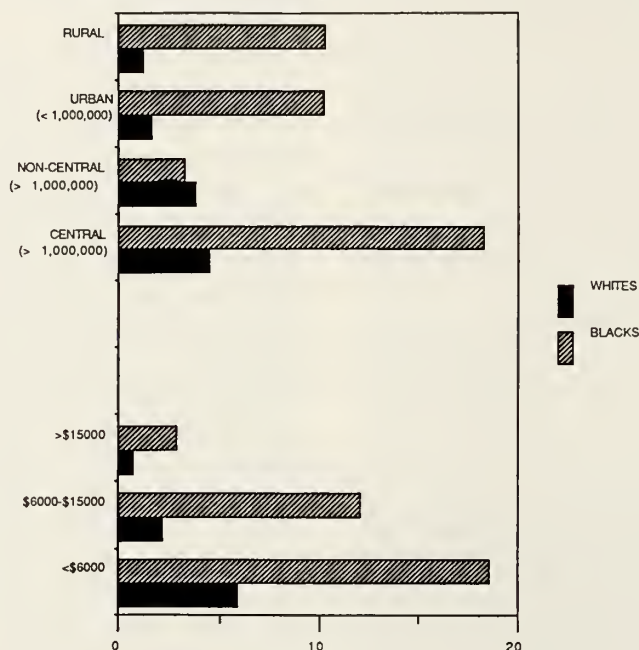
Child Abuse and Neglect

In 1986, over a million children were reported to have been physically, sexually, or mentally abused or neglected, as reported in the Study of National Incidence of Child Abuse and Neglect. There was no significant difference between males and females in neglect. Females, however, were sexually abused at 5 times the rate for males. Families with 4 or more children were more at risk for child abuse and neglect, but neither race and ethnicity, nor urban, suburban, or rural residence had any significant impact on the incidence of maltreatment.⁴¹ Child abuse and neglect are found across all socio-economic levels.

Sixty-nine percent of the abused and neglected children are under age 5, resulting in language impairment as one of the major consequences of this phenomenon.⁴² Abused and neglected children show various behavioral and physiological problems as well as academic impairment. Often they are aggressive and distractible and have poor self-control.⁴³ Many suffer depression and low self esteem, all of which can result in learning problems. Limited stimulation from the parents may result in a delay of cognitive development. An average difference of 20 IQ points can be found between abused/neglected and normally treated children.⁴³

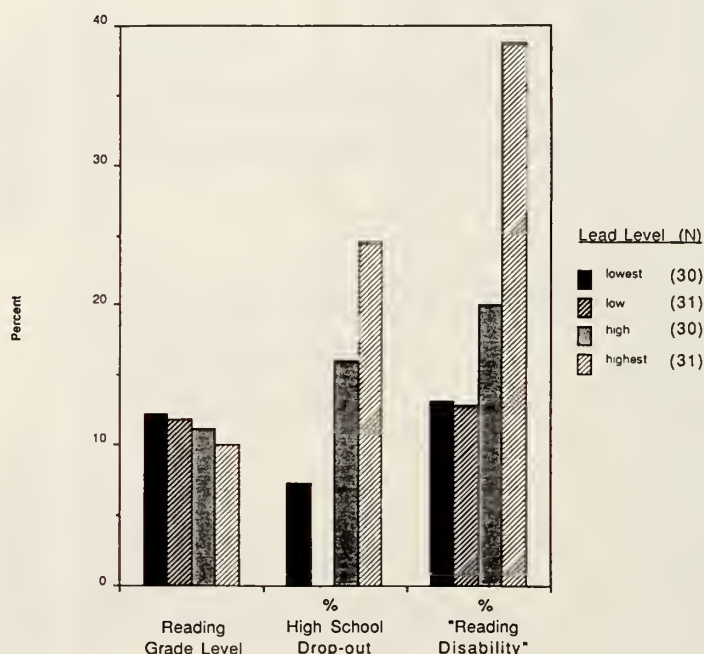
Child abuse is often measured through intentional injuries in childhood.⁴⁴ In a study of incidence rates of intentional injuries from 1979-1982 in 14 communities of Massachusetts, with populations of 100,000 or less, in-patient and emergency hospitalizations were measured by Guyer et al.⁴⁵ Their findings were

Figure 9. Blood Lead Levels in Children 6 Mo. - 5 Yr by Annual Family Income and Place of Residence



From: Mahaffey KR, et al., 1982

Figure 10. Relation of Dentin Lead Levels to Various Academic Outcomes



From: Needleman et al., 1990. Based on 132 children studied from ages 7-18.

that intentional injuries make up 3.4% of all injuries in children, leading to 9.8% of the hospitalizations and 15.7% of injury related deaths. The incidence of child battering was highest in children under 5. Of the 736 cases studied, 30 children were found to have been hospitalized twice with intentional injuries.

Malnutrition

Malnutrition is not separable from other poverty conditions. Prenatal malnutrition is generally measured by birth weight, length, and head circumference at birth. In a study of 1600 maternal-child pairs, life style, including drugs, smoking and alcohol use were also found to affect dietary intake and to have a cumulative effect on birth weight.⁴⁶ Fetal malnutrition affects from 3 to 10% of births.⁴⁷

Nutritional deprivation to the brain at critical periods, such as the brain growth spurt from 12 to 24 weeks gestation, is unlikely to be reversible.

Certain effects of nutritional deprivation are reversible, and some irreversible. Nutritional deprivation to the brain at critical periods, such as the brain growth spurt from 12 to 24 weeks gestation, is unlikely to be reversible. Once the time for a particular aspect of cell growth has passed, nothing can be done to regain it.⁴⁸ Malnourished children are deprived of energy sources, consequently impairing their ability to interact actively with the environment. The apathy resulting from protein - calorie deficiencies leads to a decrease in acquisition and processing of information, as well as to a decrease in general curiosity.

However, if programs are instituted to counteract malnutrition, children are resilient in their ability to recover from earlier deprivation, except for the brain damage noted above that occurs only during a short period in gestation.⁴⁹ Not only can improved nutrition redress past undernutrition, but enriched environmental stimulation can also have a beneficial effect in overcoming learning deficits. As some studies show, undernourished children often have a reduced head circumference suggesting smaller brain size, but they do not always show intellectual impairment.⁵⁰ Morgan notes that the reason often given is that environmental stimulation appears to be able to overcome the learning deficits resulting from a small brain size.⁴⁸

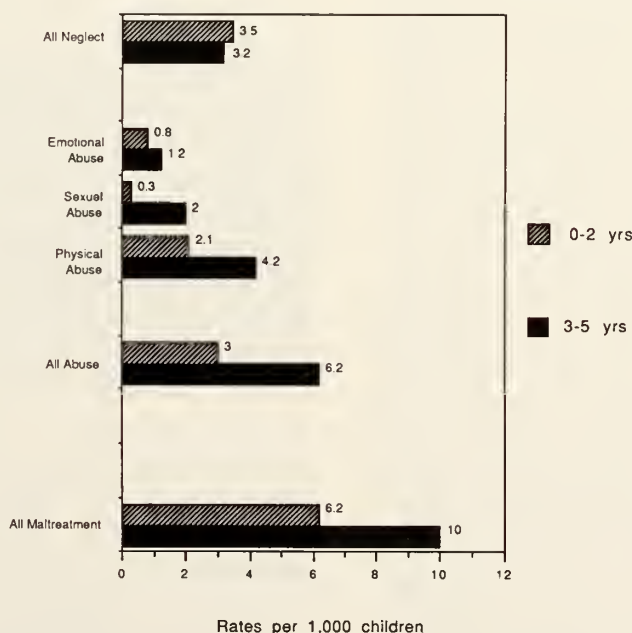
The combination of nutritional supplementation, such as that of the WIC program, and environmental enrichment such as that provided in Educational Day Care have been shown to counteract some of the effects of malnutrition.

Strategies for Prevention

While recognizing that poverty and deprivation contribute to many of these conditions, we asked what can be done to prevent risk of learning limitation, and for those already born, what can be done to ameliorate the condition.

Prevention of low birth weight lies mainly in access for all to early and informative prenatal care. Basic components of prenatal care include individual risk assessment, promotion of

Figure 11. Child Maltreatment Rates (per 1,000 children) by Type of Maltreatment and Age, 1986



From: US Department of Health and Human Services, 1988.

healthy practices, social support, and medical intervention and follow-up. The Public Health Service Expert Panel on the Content of Prenatal Care, 1989⁵¹, recommended more focused care for high risk women, including social support, and less for those less at risk who also have an intact support system. They also emphasize preconceptional care (before any pregnancy), and inter-conceptional care so that every woman is in the best possible health before pregnancy. The idea of preconceptional care reinforces the importance of school-age health education, both for health promotion and to reduce high risk behavior.

Efforts to improve the outcomes of infants born too early or too small have focused on cognitively stimulating infant day care with parent involvement. The UCLA Infant Studies Project emphasized encouragement and enhancement of parent-child interaction, providing weekly meetings of staff with parents and infants over a period of 38 months. The result was an encouraging gain of 12.9 points of the experimental group of low birth weight children over the LBW Control Group in the McCarthy Scale of Children's Abilities. This meant they were able to catch up with the normal birth weight control children.⁵²

The Infant Health and Development Project (1990) was an eight site study including 985 LBW infants randomly assigned to an experimental group who had pediatric follow-up and an educational curriculum including family support, or to a control group with only pediatric follow-up. This project demonstrated that intensive intervention effort during the first three

years of life can improve IQ scores at 36 months by an average of 6.6 points for those born under 1500g and 13.2 points from those born at 1500-2500g.⁵³

Another project was specifically targeted to poor single teenage mothers whose infants were at high risk for intellectual impairment. The experimental group children were enrolled in educational day care from 6-12 weeks of age to 54 months for 5 days a week and 50 weeks a year. By 54 months, the experimental group's IQ scores were in the normal range, and 10 points higher than a control group. Especially notable were children of mentally retarded mothers in the experimental group, who scored 22 points higher than control children of retarded mothers. In addition, "by the 54 month evaluation, mothers in the experimental group were significantly more likely to have graduated from high school and be self-supporting than were mothers in the control group."⁵⁴

... some of the disadvantages of poverty and low birth weight and even mental retardation of the mother can be mitigated and intellectual impairment avoided by attention to the cognitive development of young children. . .

All of these significant studies indicate that some of the disadvantages of poverty and low birth weight and even mental retardation of the mother can be mitigated and intellectual impairment avoided by attention to the cognitive development of young children, in conjunction with social support of their families. Programs that

strengthen the family, enhance mother-infant interaction, and provide early stimulation from zero to three have dramatic effects not only on the educational achievement of the child, but often on the self-esteem and capacity of the mother.

School health education toward a sound mind in a sound body is imperative not only for young people in their role as students, but for them as the parents they will be. Behavior in pregnancy has an impact on the resulting child. The message must go out that "It matters what you do."

Integration of these studies of risk factors for learning impairment has suggested some strategies for prevention. The following is a schematic representation of those preventive activities noted in the separate sections of this review.

Recommendations

In Education:

*Vigorous health education K to 12, including self care, nutrition, substance abuse, and sex education.

*Reproductive health education integrated with self-esteem, decision-making, and accessible contraception to decrease sexual risk-taking and unwanted/unintended pregnancies.

*Expansion of comprehensive community-based early childhood programs in compliance with Public Law 99-457, Part H.

In Pregnancy and at Birth

*Informative health care for all women before and between pregnancies, including preventive and contraceptive services.

*Comprehensive risk-responsive prenatal care for all pregnant women.

*Prevention campaigns to address all substances affecting mothers and children – tobacco, alcohol, and illicit drugs.

* Accessible, effective programs for women using illicit drugs.

* Enriched, intensive, early childhood programs for infants affected by drugs, alcohol and abuse, and their parents.

In Early Childhood

*Flexible family-centered early childhood programs widely available in all communities.

*Extension and strengthening of successful maternal and child health nutrition programs.

*Comprehensive attention to the primary prevention of lead poisoning and the identification of all children with lead burdens.

In Society at Large

*Societal commitment to address the unmet health and development needs of young children and their parents.

*Societal commitment to diminish poverty and its special damages to children.

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Perinatal Care and Learning Disorders: A Community View

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At 16 weeks, alpha-fetoprotein testing and amniocentesis can identify fetuses with neurotubular defects, and can be helpful in identifying Down's syndrome and other genetic disorders.

Influences which operate during pregnancy or at delivery are responsible for over 50% of the cases of mental retardation.¹⁻³ For many of these conditions, we have interventions which can prevent development

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of mental retardation or learning disabilities. However, timely recognition of such damaging conditions is a prerequisite. In addition, many of the family and social influences which lead to development of learning disabilities or mental retardation postnatally can be recognized prior to the birth of an infant. For some, interventions are more effective if started with the family prior to the birth of the infant.

This article reviews the major causes of mental retardation and learning disabilities that oper-

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ate prior to conception or during the prenatal period (see table 1) and discusses interventions available for these conditions. We present our experience in developing a coordinated community based program in the Blackstone Valley, the impact of those same services on perinatal

ABBREVIATIONS USED:

AFDC: Aid to Families with Dependent Children

BVPN: Blackstone Valley Perinatal Network

CPSP: Comprehensive Prenatal Services Program

FAE: Fetal alcohol effects

FAS: Fetal Alcohol Syndrome

IUGR: Intrauterine growth retardation

IQ: Intelligence Quotient

OTC: Over the counter (medications)

WIC: Women, infants, children

outcomes in our community, and make recommendations for improving preconception and prenatal services to prevent neurodevelopmental disabilities in Rhode Island.

Hereditary Disorders

Hereditary disorders and early alterations of embryonic development account for 25 to 40% of mental retardation.¹ Such disorders include inborn errors of metabolism and other single gene abnormalities, chromosomal aberrations including Down's Syndrome, and polygenic family syndromes. About 3% of newborns are affected by genetic defects, although not all lead to compromised mental ability. Personal, family, and ethnic factors are useful for identifying individuals and couples at risk. A previously affected pregnancy, a family history of genetic disease, advanced maternal age, environmental or work exposures, and membership in a high risk ethnic group identify those requiring genetic counseling or testing.⁴

Rapid advances are being made in understanding the human genome, and in developing tests for genetic disorders. Chorionic villous sampling now provides information by the tenth week of pregnancy; its use presupposes the entry of a woman into prenatal care by 6 to 8 weeks of pregnancy.⁵ At 16 weeks, alpha-fetoprotein testing and amniocentesis can identify fetuses with neurotubular defects, and can be helpful in identifying Down's syndrome and other genetic disorders.

Although recognition of genetic risk during early pregnancy is useful, if an abnormality is discovered, it commonly presents the woman with difficult personal and ethical decisions

regarding the pregnancy. The provision of genetic counseling, risk assessment, and testing prior to conception offers families the additional options of not bearing children, artificial insemination, in-vitro fertilization, surrogate pregnancy, and adoption. It also provides the woman with information to plan other aspects of her life, such as pursuing educational or vocational opportunities.⁶ Counseling does lead to long-term alteration of a couples reproductive decision-making.⁷

The provision of genetic counseling, risk assessment, and testing prior to conception offers families the additional options of not bearing children, artificial insemination, in-vitro fertilization, surrogate pregnancy and adoption.

Recognition of genetic risk early in the first trimester or before pregnancy is essential if the family is to be offered counseling, testing or interventions. As this field matures, we will need to expand the resources available in Rhode Island for genetic testing and counseling. Currently, families in Rhode Island may experience great difficulty in obtaining proper and timely genetic testing and counseling services either during pregnancy or before conception because of financial barriers. Many preconception services are not covered by the Family Planning Program or in most instances by Medicaid. Even with these limitations, the low income population may have better financial access to genetic services in Rhode Island than women with private insurance. During pregnancy, such services are made available to low income

women through the state Medicaid and CPSP/Rlte Start Programs.

Most medical insurance programs in Rhode Island do not provide coverage for genetic counseling. Many do not provide coverage for chorionic villous sampling although they do cover amniocentesis, even though early care for a genetic defect, including use of chorionic villous sampling, may be less expensive than when testing is delayed until amniocentesis is possible. In Rhode Island, both prenatal and preconcep-

Table 1. Preconception and Prenatal Causes of Mental Retardation and Learning Disabilities

I. Causes Amenable to Preconception, or Preconception and Prenatal Intervention

A. Reproductive Decisions

- Unwanted or unplanned pregnancy
- Hereditary and genetic disorders
- Age extremes

B. Maternal (or Paternal) Habits

- Inadequate nutritional status
- Smoking
- Alcohol use
- Substance abuse

C. Medical and Psychiatric Disorders

- Maternal infections or infectious susceptibility
- Chronic diseases and medication use
- Maternal or paternal psychiatric disorders

D. Family Dysfunction

- Family violence
- Family neglect
- Inadequate parenting competency

E. Social Deprivation or Dysfunction

- Inadequate subsistence resources, homelessness
- Inadequate understanding of and access to health care
- Inadequate knowledge about reproduction and family planning
- Inadequate knowledge about family life skills
- Toxic work environment

tion availability of genetic testing and counseling, including chorionic villous sampling, should be assured through voluntary or legislatively mandated expansion of third party coverage.

Alcohol and Substance Abuse

A second set of influences leading to mental retardation and learning disorders are those that damage the fetus and its central nervous system either directly or through effects that promote premature delivery or intrauterine growth retardation. Most prominent among these causes are alcohol, cocaine, and other substance abuse.^{8,9} Prescription and over the counter drugs, and other chemicals to which the woman may be exposed at home or through the workplace also may directly damage the fetus. The amphetamine family of substances, including cocaine, crack, ice, and drug cocktails containing them may directly damage the fetus' brain, or lead to placental inadequacy, abruption, or prematurity which in turn may lead to damage.¹⁰

Ideally, screening for alcoholism should occur before conception, because the nature of alcohol . . . is such that 6 months or more may be required to attain abstinence . . .

Although it has not received the public attention given to the effects of crack and cocaine, fetal exposure to alcohol may result in more severe and untreatable defects in infants.¹¹ Fetal alcohol syndrome is the leading preventable cause of mental retardation in the nation today.¹² Studies over the past 15 years suggest that there is no

known safe level of exposure to alcohol during pregnancy. In a study of predominant middle class white married women, even moderate drinking was associated with an average 5 point decrease in IQ and a 3 fold increase in risk of an offspring having an IQ less than 85.¹³ The young executive woman who has a glass of wine at a business lunch, another at the end of the day, and a third over dinner is exposing her fetus to significant risk of mental retardation and learning disorders.

Alcohol use as well as alcohol abuse is of concern during pregnancy. To be most effective, education regarding alcohol use should occur early in the first trimester when the fetus is most susceptible. Ideally, screening for alcoholism should occur before conception, because the nature of alcohol and other substance abuse is such that 6 months or more may be required to attain abstinence, and subsequent relapses can be expected.

To be of value, such case identification must be accompanied by availability of appropriate treatment programs. Many alcohol and substance abuse programs are based on models effective for white middle class men. Women with substance abuse problems require programs which provide safe environments specifically responsive to their needs. Interventions useful for such women include counseling about associated problems including prior (or current) family violence, such as physician and sexual abuse during the woman's childhood, eating disorders, and assistance with subsistence, educational, and vocational needs. For women who already have children, such programs should support the development

of the women's parenting ability as part of treatment rather than deferring such activity until after completion of the substance abuse program.

On an annual basis, we can expect at least 30 infants in Rhode Island to be born with fetal alcohol syndrome (FAS), and another 45 to 50 with fetal alcohol effects (FAE).^{8,11} Many individuals with FAS or FAE are never identified because the effects of alcohol often are not evident at birth. Such infants, particularly those with FAS, are usually unable to live independently in society. Virtually all FAS and many FAE infants cannot progress beyond a third or fourth grade educational level and require special educational resources. The problems they encounter in school may be only the beginning of a legacy of problems with which such individuals, and the societies they live in, will have to cope. These infants frequently become problem teenagers and as adults become homeless, or find homes within our prisons or other institutions. The total lifetime cost to society for a fetal alcohol damaged infant has been estimated at 1.4 million dollars. Thus in Rhode Island, we annually accrue a future cost of between 30 and 70 million dollars, ten times the long-term cost of the state early retirement program of 1990.

The maternal and child aspects of the impact of alcohol in Rhode Island was not discussed in either the 1985 or 1987 studies commissioned to assist in planning state drug and alcohol efforts.^{14,15} However, state agencies have begun to put in place funding for evaluation and treatment options. Currently the Rhode Island Division of Substance Abuse is working with others in the state to establish a

residential facility which will accept women accompanied by their infants. Although this facility will help, its projected 12 beds will be filled quickly and will not fully meet the need of Rhode Island women. Programs such as the Eastman House, the Talbot House, and other services through state-wide and community-based agencies are helping, and in some cases expanding, to better serve this population.

The problems that Fetal Alcohol Syndrome children encounter in school may be only the beginning of a legacy of problems with which such individuals, and the societies they live in, will have to cope.

Substance abuse treatment agencies must manage the complexities of multiple state and third party funding sources. These often have different criteria, waiting lists, and program objectives. Coordination of the resources available from the State Departments of Human Services, Health, Education, Children and Their Families, and Mental Health, Retardation and Hospitals is necessary to meet the needs of substance abusing women. This can become an overwhelming task for the women and for the treatment agency attempting to work with them. There is a need in Rhode Island to increase coordination of the components required for effective comprehensive treatment of such women and their families.

Cutbacks or restrictions in the growth of such programs may be perceived as financially and politically cost effective in the short term, but carry major long term liability for the state. The recent development of ac-

tive case management of service provision by third party carriers, including for mental health and substance abuse, also may restrict availability of services. Where inappropriately carried out, such case management may be effective in limiting costs to the insurance company. However, the ultimate effect of such cost saving may be to transfer both initial and much higher lifetime costs to the public sector and taxpayer. Therefore the state needs to vigorously monitor such case management activities, and if they are found to be barriers to treatment, they should be regulated accordingly.

Low Birthweight

There are a number of influences that lead to a low birthweight delivery, including premature labor and intrauterine growth retardation (IUGR). In 1985, 6.7% and 6.3% of all newborns weighed less than 2,500 grams in the United States and Rhode Island respectively.^{16,17} IUGR increases by 5 to 10 fold the risk of long-term neurologic disabilities including lower intelligence, seizures and cerebral palsy, as well as learning disabilities, school failure, and behavior problems, in comparison to the experience of non-IUGR infants.^{18,19} Premature delivery not accompanied by IUGR also increases the risk of such morbidity, with the risk increasing dramatically as birthweight decreases below 2,000 grams.^{20,21}

Psycho-social, medical, and obstetric problems all contribute to the occurrence of low birthweight deliveries.²² Many of those with IUGR have placental insufficiency and fetal malnutrition as a common pathway. Of note, more than half the cases of IUGR are linked not to maternal

medical disease, but to various maternal behavioral characteristics.²³ Interventions to ameliorate their contribution to low birthweight outcomes is a major goal of routine prenatal care.

The Institute of Medicine in *Preventing Low Birthweight*¹⁶ supports the concept of the primary prevention of low birthweight. The Low Birthweight committee suggested that an attempt to identify and reduce the risks to pregnancy, particularly the risks of low birthweight, is worthwhile and should be extended into the prepregnancy period. As a follow-up to this report, the Expert Panel on the Content of Prenatal Care was commissioned by the United State Public Health Service, Division of Maternal and Child Health, and the National Institute of Child Health and Human Development. Its report, *Caring for Our Future: The Content of Prenatal Care*,²⁴ also emphasized that the objectives for prenatal care are to promote the health and well being of the women, the fetus and the family. They suggest that the prenatal period provides an opportunity to look beyond pregnancy and delivery to identify the resources essential for further healthy development of parents and infants.

About 40% of births in the United States are unplanned.

Identification is a prerequisite to intervention. Therefore, comprehensive risk assessment is required to guide quality prenatal care. A number of risk factors are recognizable before conception, and may be alterable only by preconception or interconception interventions, including the planning of preg-

nancy and the use of adequate birth control.²⁵ Such conditions are exemplified by short inter-pregnancy interval, being underweight or otherwise nutritionally compromised, not being immunized for rubella, or having uncontrolled chronic diseases such as diabetes or chronic hypertension.

About 40% of births in the United States are unplanned.²⁶ Preterm birth and IUGR are likely to be more common among women with unplanned or unwanted pregnancies, particularly when associated with poverty.²⁷ Therefore, family planning programs contribute to the reduction of the prevalence of mental retardation and learning disabilities. In Rhode Island, family planning services are provided through private physician offices, community health centers, free-standing programs, and hospital outpatient departments. Comprehensive assessment of risks to future pregnancy ordinarily does not occur as part of either regular family planning visits, or as part of pregnancy testing. Approaches to such risk assessment have been developed. For example, programs in North Carolina use a self-administered checklist which have been shown to identify an average 6.8 risks per women when completed at a family planning visit.²⁸

The identification, education, and assistance in modifying such risks empowers women to improve their chances of having a healthy pregnancy even before conception. The Department of Health has encouraged such activities and should consider a major statewide campaign to assist primary care physicians and obstetricians in all practice settings to offer preconception risk assessment at appropriate contacts with women. Such op-

portunities include family planning visits and other contacts such as college entrance, work, or premarital examinations.

Other risk factors for low birthweight become evident only during pregnancy. Effectiveness of intervention for some is improved by initiating prenatal care early in the first trimester. Improvement of nutritional status, treatment of hyperemesis, treatment of infections including asymptomatic bacteria, and modification of highly stressful family or work conditions are examples. Other conditions, such as placenta previa or abruption, preeclampsia, gestational diabetes, isoimmunization, oligohydramnios, polyhydramnios, and preterm labor may not occur until late in pregnancy and require ongoing assessment.

Smoking is perhaps the single most preventable risk factor for low birthweight delivery, and associated mental retardation and learning disorders.

Smoking is perhaps the single most common preventable risk factor for low birthweight delivery, and associated mental retardation and learning disorders. About 14% of low birthweight births are directly attributable to maternal smoking.²⁹ Ideally women should be helped to stop smoking before conception; however, intervention as part of prenatal care should be available and offered to every pregnant woman who smokes. While approximately 20% of women stop smoking on their own during pregnancy, this can be increased to 40-50% by effective programs.³⁰ For this reason, the Department of Health for several years has of-

fered Rlte Start reimbursement for organized smoking cessation programs. In spite of this, very few programs that are specifically tailored to pregnant women are available in Rhode Island. This is particularly true for women with household incomes less than half of the federal poverty guidelines (those eligible for Rlte Start support for smoking cessation). Prenatal providers and those specializing in smoking cessation should collaborate to make such services readily available throughout the state. Means of certifying Rlte Start reimbursement eligibility for individual cessation programs (the means by which most women stop smoking), and group programs should be developed.

Labor

Influences may arise during labor which lead to mental retardation and learning disabilities. Although commonly perceived to be the major cause of such outcomes, several recent reviews suggest that not more than 10% of cases are due to intrapartum events such as neonatal asphyxia, intracerebral bleeding or severe metabolic disorders, the causal pathways usually implicated.^{31,32} The poor association of intrapartum hypoxia with neurodevelopmental handicaps in children is reflected in the fact that 96.1% of infants with 5 minute Apgar scores of 0 to 3 will be of normal intelligence. Of all those under 2,500 grams about 2% are estimated to have mental retardation caused by intrapartum asphyxia.^{32,33}

Intrapartum hypoxia and abnormal fetal heart rate patterns occur much more commonly among fetuses which have suffered chronic placental or other vascular insufficiency prior to

labor. Acute intrapartum asphyxia severe enough to cause permanent brain damage usually is accompanied by acute damage to multiple other organ systems as well. In the absence of such damage, it is likely that a neurodevelopmental deficit occurred due to an antepartum rather than intrapartum insult.³⁴

The poor association of intrapartum hypoxia with neurodevelopmental handicaps in children is reflected in the fact that 96.1% of infants with 5 minute Apgar scores of 0 to 3 will be of normal intelligence.

Even with proper monitoring during labor, some catastrophic intrapartum events such as abruption, cord prolapse, or intraventricular hemorrhage may occur resulting in permanent damage to the infant. Hospitalization at or transfer to tertiary centers, such as Women and Infants Hospital, of women with premature rupture of membranes, preterm labor, or other conditions likely to result in a high risk delivery, will allow optimal birth management and neonatal intensive care unit availability. These may decrease perinatal morbidity, including that resulting in mental retardation or learning disabilities.

Postnatal Causes

In addition to those which affect the infant prior to birth, an additional set of influences can be identified which if not recognized and treated before birth may lead to the development of a learning disorder following birth. These factors generally are related to the parent's mental, emotional, and economic state and the social supports available to them.^{35,36} Child

abuse, neglect, emotional deprivation, non-organic failure to thrive, and lack of adequate parenting during infancy and early childhood years all contribute to a child physically, emotionally, or maturationally unable to be successful in school.

Family violence is the most dramatic of such causes and often begins even before the pregnancy.³⁷ Battering is likely to escalate during pregnancy, and continue after delivery. Spousal abuse may be associated with abuse of children by either the perpetrator or victim of the marital violence. These children also are likely to suffer from the low self esteem, depression, high anxiety and alcohol or other substance abuse that commonly occurs in such families.

Even when battered women present to emergency rooms following abuse, only about one-third are recognized as having suffered such abuse. Identification of victims occurs even less frequently during routine prenatal office visits. Recognition must be accompanied by the availability of shelters and support services capable of providing effective interventions. If these are used, the family, or the mother by herself, may be more capable of providing the infant with a safe and supportive environment, both before and following birth.³⁸

Other family dysfunction sometimes associated with neurodevelopmental disabilities include teenage pregnancy, psychiatric disability in a parent, and lack of social supports. Affected families are at high risk of being unable to successfully parent an infant with resultant behavior disorders, poor language skills, and poor preparation for school. Recent re-

views^{39,40} have found that comprehensive care programs for multi-risk families are expensive (cost of intervention per family of approximately \$32,000) but provide considerable financial savings (approximately \$160,000 per family; net benefit of \$128,000).

Currently, we have a number of programs in Rhode Island which provide services to such families, although this care is often not coordinated with other agencies and health care givers. These families may be identified

Table 1. (cont.)

II. Causes Active During Pregnancy

A. Genetic

Chromosomal errors (eg, inborn errors of metabolism)
Single gene disorders (eg, Down's syndrome)
Polygenic disorders

B. Toxic Influences on Embryonic Development

Alcohol
Other substance abuse
Prescription and OTC drug use
Chemical exposures (work or home)

C. Maternal Infections

Cytomegalovirus
Toxoplasmosis
Rubella

D. Prematurity, Placental Insufficiency, Fetal Malnutrition and Intrauterine Growth Retardation

Smoking
Postmaturity
Preeclampsia
Abruption and previa (including cocaine induced)
Multiple pregnancy
Autoimmune diseases
Rh disease

III. Intrapartum Causes (hypoxia-asphyxia)

Abruption
Macrosomia and dystocia
Abnormal presentation
Multiple pregnancy
Cord prolapse
Iatrogenic

initially by various social services before pregnancy. During pregnancy they may receive attention from care coordinators employed at Department of Health Comprehensive Prenatal Services Program (CPSP) sites and frequently receive Medicaid, AFDC, food stamps, WIC benefits, and the attention of a Department of Human Services social worker. Following birth, they may receive support from the Department of Children and Their Families, including through its Comprehensive Emergency Services program. Community mental health centers, substance abuse programs, and our legal and penal systems may all become involved. As we develop an Early Start program in compliance with Public Law 99-457, these families are likely to receive additional services. Thus, already we are making a major investment in these families, in keeping with the cost estimates cited above.

The state supported comprehensive teen pregnancy programs, including those that are school-based are valuable in supporting one group of multi-problem families at increased risk of producing mentally retarded or learning disabled infants. These programs should be expanded to decrease the current waiting lists, and to include contraceptive services which might prevent many such pregnancies, or repeat pregnancies.

For many women, including those from multi-problem families, psycho-social concerns are often overwhelming, may delay entry into prenatal care, and may result in frequent non-compliance with care. For this reason, the Rhode Island Department of Health has modified its CPSP and RIte Start program to emphasize active care coordination of

high risk women throughout pregnancy. By linking these programs to its pediatric programs, the Department of Health has encouraged the continuation of care coordination services through infancy.

These initiatives have placed Rhode Island in a leading position nationally in responding to the needs of pregnant woman and their infants. Unfortunately, the ability of CPSP/RIte Start care coordinators to be effective may be hindered by difficulty in obtaining needed social and family support services, and coordinating them when available. The multiple agencies involved, and differing eligibility and waiting criteria all complicate the ability of families to access needed services. Coordination among state agencies and community-based networking to make services available is needed to organize effective services for high risk families.

One Community's Response

Many of the hereditary, substance abuse, social, medical and obstetric risks that lead to a neurodevelopmentally compromised infant are best managed if identified early, even prior to conception. Effective preventive intervention is often dependent on the availability of accessible reproductive care, coordination of this with subspecialty services, and with the provision of other social and family support services. Because of this, local communities must assume major responsibility for the primary care needs of the maternal and child health population of the state. Such concerns are best cared for in local private physician offices and community health centers. This approach was initiated by the Brown University/Memorial Hospital of Rhode Island Department of

Family Medicine through its Family Care Center in 1982.

In 1986 representatives of the Department of Family Medicine, the Family Care Center, the health centers in Pawtucket and Central Falls, and the Visiting Nurses Services of Pawtucket and Central Falls, recognized the need to work cooperatively rather than competitively to provide prenatal services in Central Falls and Pawtucket. We formed the Blackstone Valley Perinatal Network (BVPN) and soon after received March of Dimes funding to provide transportation to women to encourage entry and compliance with prenatal care.

We recognized that a major portion of the morbidity experienced by low income or socially disadvantaged families is due to either psycho-social problems or obstetric problems best dealt with prior to their becoming major problems for the infant. Thus we saw the need to strengthen and expand our community-based primary care maternity capacity. Our goal is to respond comprehensively and in a coordinated and ongoing manner to the problems presented by women in their reproductive years, including prior to conception, prenatally and postnatally.

In 1987 the BVPN received support to be one of five federal Bureau of Maternal and Child Health national demonstration community networking projects. With this funding we have identified and prioritized maternal and child health concerns in our community and begun developing interagency guidelines to coordinate care of families affected by such problems. We have developed programs to encourage prevention of unwanted or unplanned pregnancies and to encourage early en-

try to prenatal care. In 1988 the Network identified substance abuse by pregnant women and mothers as the number one maternal and child health concern in our community. This resulted in our developing guidelines for the care of women with alcohol, cocaine and associated problems. Most recently, this led to a successful application to the federal Office of Substance Abuse Prevention for a two million dollar five year (1990-95) award to expand the Network to include substance abuse treatment facilities and to coordinate community-based responses to this problem.

With the support of the Rhode Island Department of Health's Family Life and Sex Education Program, the BVPN works with the Blackstone Valley Community Action Program to operate a Family Life project in our community. Through this, we are working with area schools, social service agencies, churches, and other community groups. Our focus is to prepare adults, including parents and teachers, to be able to help teenagers and young adults faced with decisions regarding their sexuality and risk-taking behaviors. The program also works directly with teens. Through this project we are encouraging family involvement in such decisions, and abstinence or appropriate family planning until pregnancy is a desired, planned event. We also are promoting the recognition of the value of preconception care and preparation for a healthy pregnancy.

We have modified our family planning and pregnancy test visits to include completion of a preconception risk assessment questionnaire and to provide basic preconception education. Accomplishing this is at times hindered by staffing limitations

but has been received positively by women and by the women's primary care physicians.

Those women most at risk in our community are also the most likely to delay entry to prenatal care or not obtain it at all. Some may not be aware of the availability or importance of prenatal care. Immigrants, especially those with little fluency in English and teenagers are among those who may not be aware of the Rte Start program or resources available from Medicaid. Indeed, in an anthropologic study of women delaying entry to prenatal care until beyond 20 weeks we found several women who did not know what the word "prenatal" means. More affluent women may not be aware of the importance of early prenatal care. Because of this, with March of Dimes and Federal Bureau of Maternal and Child Health support we initiated the Healthy Baby Lottery, now entering its second year. Through this we encourage word of mouth publicity about the importance and availability of prenatal care in our community and also encourage office staff to be supportive and enroll women as soon as possible.

... we are encouraging family involvement in such decisions, and abstinence or appropriate family planning until pregnancy is a desired, planned event.

Has this approach made a difference? A true measure of the value of a community-based program is its impact on the total community incidence of neonatal mortality and morbidity, not just that experience for women enrolling in a program for care. The prenatal care pro-

viders of the BVPN, the Family Care Center and the Blackstone Valley Community Health Care, Inc. health center in Pawtucket and Central Falls provide virtually all care to the low income population of the region. Such women constitute over 60% of those delivering from Central Falls and Pawtucket. For the five years, 1983-87, the most recent for which state vital statistic have been finalized, our experience has been encouraging. For target area census tracts rated as poverty level, the neonatal (first month of life) death rate was 5.8 per thousand, that for low income census tracts was 6.2 per thousand. This is in comparison to a rate of 6.9 per thousand for all deliveries in the state during the same interval.⁴¹

Conclusion

A majority of cases of mental retardation and learning disabilities have their origins in conditions operating before or during pregnancy. Interventions may occur during pregnancy or prior to conception. Comprehensive assessment, and coordinated response to psychosocial, medical, and obstetric risk are required for effective preventive intervention. Community-based networking of services coupled with the tertiary services available through Women and Infants Hospital holds promise for reaching women and families at highest risk.

Rhode Islanders should be proud of the progressive and innovative prenatal programs offered by our state. However, with modest investment in additional community-based networking of services throughout the state, it is likely that our ability to promote the birth of healthy babies to families prepared to raise them can be in-

creased. During a era of increasing financial deficits, we need to remember that our deficits in human investments are just as real and urgent. From a long term perspective such investment will be cost-effective, and is a measure of the caring dimensions of our society.

The Blackstone Valley Perinatal Network has received support from the federal HRSA Bureau of Maternal and Child Health, from the federal Office of Substance Abuse Prevention, and the March of Dimes.

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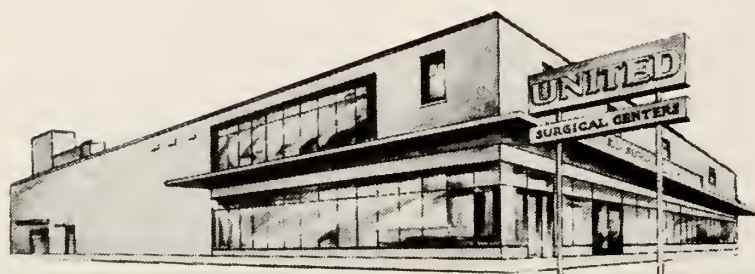
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The Role of the Physician in Early Intervention Screening for Infants and Toddlers

Thomas T. Kochanek, PhD

... newborns have a host of adaptive responses prepared to resist respiratory occlusion, help protect body temperature, and seek and obtain nourishment.

Unprecedented interest and concern for infants and young children have recently emerged. The genesis of this interest is multi-faceted, and emanates from demographic, political, and legislative initiatives. Of these, perhaps the most powerful and persuasive is the robust research base which has developed over the past decade.

Advances in Research

Until recently, the learning capabilities of infants were seriously underestimated. Recent findings have revealed that newborns have a host of adaptive responses prepared to resist respiratory occlusion, help protect body temperature, and seek and obtain nourishment.¹ Newborns possess sophisticated sensory and perceptual systems which allow for discovery and analysis of their en-

vironment.² In fact, response to touch in the fetus has been reported as early as two months after conception.³

A second impressive body of literature includes numerous studies which have attempted to identify the outcomes of early intervention services for infants, toddlers, and their families. More specifically, programs designed to serve children from socially, educationally, and economically disadvantaged families have demonstrated several positive findings. With respect to child outcomes, of the nine studies⁴ which reported serial IQ scores, six revealed statistically significant differences between experimental and comparison groups. Of greater importance is the fact that infancy intervention projects support an intensity hypothesis; that is, home visits alone did not substantially alter intellectual development at age two. However, home visits in addition to medical and educational intervention and parent focused training produced moderate ef-

fects on IQ. Furthermore, providing day care plus family services were associated with the greatest improvement in intellectual development.

With respect to long term effects, the Consortium for Longitudinal Studies⁵ conducted a 20 year follow-up study of project participants and reported three principal findings: (1) program recipients were less likely to be retained or referred for special education services; (2) experimental group children were more achievement oriented; and (3) enrolled parents had higher

ABBREVIATIONS USED:

DDST-R: *Denver Developmental Screening Test Revised*

IQ: *Intelligence Quotient*

LBW: *Low birth weight*

NICU: *Neonatal Intensive Care Unit*

PL: *Public Law*

SAT: *Scholastic Aptitude Test*

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educational and occupational aspirations for their children than control families. Similar findings were reported by Schwienhart and Weikart⁶ who indicated that program graduates were employed more often, had higher incomes, and made less use of public assistance programs than did comparison groups.

. . . this comprehensive, early intervention system revealed substantial promise in reducing the risk of developmental disability in low birth weight, premature infants . . .

With regard to infants at biologic risk, attention has been primarily focused on low birthweight (LBW) cohorts. While a number of intervention studies have shown improved outcomes for LBW infants,⁷ a recent comprehensive study conducted by the Infant Health and Development Program⁸ is most encouraging. In brief, this multi-site randomized clinical trial was developed to evaluate the efficacy of early child development, family support, and systematic pediatric follow-up in reducing developmental, behavioral, and other health problems among LBW, premature infants. The program was initiated on discharge from the newborn nursery and continued until three years of age. The intervention group received comprehensive pediatric follow-up in addition to home visits, parent group meetings, and beginning at 12 months, attendance by the youngster in child development programs. Overall, data collected at age 36 months revealed that the intervention

group had significantly higher mean IQ scores than the comparison group, and also demonstrated fewer maternally reported behavior problems. The Infant Health and Development Program concluded that this comprehensive, early intervention system revealed substantial promise in reducing the risk of developmental disability in LBW, premature infants, and furthermore, documented the apparent safety of intervention with a biologically vulnerable population.

Demographic and Political Factors

Beyond these impressive research data, a number of other forces have also prompted interest in young children. Firstly, the need for high quality child care is now universal and no longer restricted to the needs of children in poverty. While approximately 34% of all mothers with children less than three years of age were engaged in positions outside of the home in 1975, the corresponding figure for 1987 has nearly doubled. Projections indicate that approximately 70-80% of mothers of preschool children will become members of the workforce in the next decade (US Department of Labor, 1987). These trends have stimulated several lines of interesting and controversial research inquiry,^{9,10} and generally indicate that studies completed to date on the effects of infant day care have too many methodological problems to serve as the basis for alarm about the consequences of early non-parental care.

Secondly, the increasing prevalence of illiteracy and declining SAT scores of American youth compared to their coun-

terparts in other industrialized nations have contributed to an evolving perception that children in the United States are not prepared to successfully compete in world markets.¹¹ This economic threat has led to a series of education reform initiatives which invariably include a major component directed at preschool populations. Increasingly, early childhood programs are being evaluated for their investment potential, and there appears to be consensus in industry that preschool intervention is a prudent investment.

Legislative Initiatives

Finally, within the last three years, the Congress has enacted several pieces of bold legislation which are designed to exert enormous influence on the lives of young children and their families in the next decade. One such initiative is the Family Support Act which promotes major reforms designed to improve the life chances of disadvantaged children by addressing their health and education needs as well as the vocational needs of their parents. As such, the Act has been characterized as a "two generation prevention program" which attempts to influence both child and family well-being.¹²

... the Congress has enacted several pieces of bold legislation which are designed to exert enormous influence on the lives of young children and their families in the next decade.

Similarly, P.L. 99-457 (Part H) was passed in order to implement comprehensive, family-centered programs for develop-

mentally disabled and vulnerable infants and toddlers. With regard to the structure of the law itself, while states are provided with considerable latitude in the planning process, fourteen essential components must be addressed. Perhaps one of the most complex questions within the statute pertains to who should be served in an early intervention system. The law provides a minimum threshold for answering this question identifying three populations of children: (1) those with significant developmental delay; (2) those with diagnosed physical or mental conditions resulting in developmental delay; and (3) those who have experienced adverse biological and/or environmental insults which, in combination, result in developmental delay. While these categories provide a skeletal framework for defining an eligible population, they are not sufficiently detailed to craft statewide policy. As such, each state must develop a uniform, systematic process in order to promptly and accurately identify developmentally disabled and vulnerable infants and toddlers. Within this model development process, several essential questions are apparent.

- What are the early and most reliable and valid indicators of developmental disability in infancy and early childhood?

- What indices/measures exist which ensure accurate identification of this population? Are there optimal times at which these measures should be used?

- Who should be responsible to use these indices/measures? Who are the primary reporters of information on known or suspected disability?

- What is the cost and intru-

siveness of such a system?

While precise answers to the above questions do not exist, fortunately a body of literature is available which sheds light on the current system, and also provides guidance for the future. With respect to the effectiveness of existing early identification procedures, available epidemiologic data underscore significant system deficiencies. Specifically, both regional and national data¹⁵ reveal that relatively few children (ie, 1%) are enrolled in early intervention programs. Moreover, since this number is substantially less than the occurrence of disabling conditions in children in the general population,¹⁴ and since early identification systems primarily depend upon referrals from health care providers, child care agency staff, and parents themselves, the inadequacy of the current system is apparent. Simply stated, only a small proportion of children who manifest serious learning and behavioral problems subsequent to school entry are identified during the infant/toddler period.

These data have prompted considerable discussion in the pediatric community,^{15,16} and in fact, have led to the conceptualization of a process called developmental surveillance.¹⁷ Briefly, the primary health care provider serves as the centerpiece of this process; however, unlike previous screening initiatives, surveillance does not restrict itself to isolated developmental examinations, but rather includes ongoing appraisal of the overall care giving environment. The principles upon which this surveillance process are based are well established empirically, and include the following tenets:¹⁸

Essential Components of a Screening Process

Screening as Services

The sole purpose of screening is not to exclude children and families from service systems. Screening should be viewed as the initial step in service provision, and as such, is developed to gather information concerning child and family needs, and ensure linkage with appropriate, community-based resources and programs.

Multi-Factorial Screening Components

Numerous research studies have repeatedly verified that learning, behavioral, and social competence in adolescence cannot be predicted independent of a child's caretaking experiences.^{19,20,21} As such, screening models must include information not only on biological circumstances and developmental competence, but also be amplified to assess family needs, strengths, resources, support systems, and the quality and quantity of the child/parent relationship.

Multiple Information Sources

Predictive validity studies^{22,23} have indicated that early identification models which rely on single factors are replete with decision making error. Consequently, reliable screening systems must include not only multiple sources (eg, product of biological, developmental, and environmental factors) but also multiple reporters (eg, professionals, parents, family members).

Periodicity

Due to significant variation in

child developmental pathways as well as ongoing changes in family status, all children and families should participate in screening on multiple occasions between birth and three years of age. Judgments regarding the need for further evaluation should be based upon evidence of jeopardy at individual time points as well as from determination of cumulative risk.

Dual Level Screening

Several investigations have concluded that single stage screening models which focus upon adverse macroscopic factors (eg, low birthweight, respiratory distress) are highly likely to over identify children in need of early intervention services. As such, the merits of two-tiered models have been advanced²⁴ in which essential, valid information can be collected at two levels of specificity in order to determine the need for in-depth, multi-disciplinary team evaluation.

Promising Experimental Models

A project which fully embodies the principles advanced above has been recently underwritten by the US Department of Education.²⁵ Consistent with the concepts inherent within the developmental surveillance process, the PREDICTS model is designed as a two-tiered, multi-dimensional, ongoing process which involves systematic data collection at four time points (ie, neonatal period and at 6, 12, and 24 months of age).

Level I screening, the first stage of the process, is intended to be population based and involves the collection of status information (eg, maternal education, birthweight). The objec-

tive of the Level I screening is simply to identify children in need for more in-depth follow up, and as such is brief and designed to include highly significant yet non-redundant components.

Level II screening, conducted within the home, is a comprehensive process which includes information on the child's developmental competence, family strengths, needs, and support systems, and caregiver/infant

Table 1. Level I and II Screening Components

	Neonatal Period	Level I Screening		
		6 Months	12 Months	24 Months
1. Established Conditions				
chromosomal anomaly				
genetic disorder				
inborn errors of metabolism				
neurological disorders				
sensory impairments				
infectious diseases				
congenital malformations				
toxic exposure				
developmental delay				
2. Child Characteristics				
birthweight	X	-	-	-
gestational age	X	-	-	-
Apgar Scores	X	-	-	-
NICU treatment	X	-	-	-
no. and length of hospital admissions	-	X	X	X
growth parameters	-	X	X	X
no. of confirmed instances of otitis media	-	X	X	X
hearing assessment	-	X	X	X
vision assessment	-	X	X	X
DDST-R	-	X	X	X
lead screening	-	-	X	X
3. Parental Demographics				
maternal education	X	-	-	-
maternal age	X	-	-	-
maternal marital status	X	-	-	-
no. of persons living in home	X	-	-	-
4. Parental Characteristics				
no/inadequate prenatal care	X	-	-	-
developmental disabilities	X	-	-	-
mental health tx.	X	X	X	X
child protective services	X	X	X	X
substance abuse	X	X	X	X
chronic illness	X	X	X	X
Level II Screening				
Child Characteristics				
Mullen Scales of Early Learning or Developmental Profile II				
Parental Characteristics				
Family Resource Scale* and Family Support Scale				
Mother/Child Interaction				
HOME**				

*Dunst, CJ, Trivette, CM & Deal, A. (1988). Enabling and empowering families: principles and guidelines for practice. Cambridge, MA: Brookline Books.

**Caldwell, B. & Bradley, R. (1979). Home observation for measurement of the environment Little Rock, AR: University of Arkansas.

interaction. The major goal of Level II screening is to identify children in need of a multi-disciplinary team evaluation in an early intervention program. Although details regarding Level I and II screening processes²⁶ and the rationale for instrument selection are presented elsewhere,²⁷ Table 1 summarizes the data elements for each stage of the process.

... only a small proportion of children who manifest serious learning and behavioral problems subsequent to school entry are identified during the infant/toddler program.

Since the inception of Project PREDICTS, approximately 3400 infants have received Level I screenings, and nearly 1000 children and families have participated in the Level II component. Statistical analyses of the neonatal data²⁸ appear to indicate that the origins of vulnerability reside both within the biological and ecological domains.

Data in this study also suggest that the prevalence of developmentally disabled and vulnerable children varies considerably by age, and that specific measures contribute differently to decision-making, dependent upon the age at which they are collected. Newborns who emerge from such surveillance models differ from those identified at 18 months of age, and this finding reinforces the justification of recurrent or periodic screening.

It is critical to note that the above findings are derived from the Level I screening process for newborns only, and do not re-

flect data collected at 6, 12 and 24 months of age by physicians during child health supervision visits. Field testing of this component of the screening process is currently underway, and clearly, the full participation of physicians is critical to effective implementation.

Implications

Research conducted over the past decade with infants and preschool children which has confirmed the positive outcomes of early intervention have rendered moot the query, "is it effective?", and have identified new, critical questions which must be answered: "To whom and how should early intervention services be provided?"

Information derived from a comprehensive research base suggests that developmental surveillance models hold the most promise for identifying developmentally disabled and vulnerable young children; and moreover, that physicians must assume a central role in such models. Furthermore, if such models are to be effective, they must be multivariate, child and family focused, and undertaken on a periodic basis.

While the design and essential components of developmental surveillance models are clear, the support systems necessary for ensuring full compliance and implementation are less well developed. For example, collecting information on child and family needs during well child care visits is solidly grounded; however, the training and technical assistance which must be provided to health care professionals to ensure reliable and valid data collection are presently unavailable. Therefore, an urgent need exists for

the development of a sequential series of competency based training activities; such experience should be initiated and underwritten by the collaborative efforts of universities, state agencies, and the American Academy of Pediatrics.

Secondly, although the physician assumes a prominent role in the implementation of comprehensive, population based surveillance systems, screening cannot occur in isolation. In order for such initiatives to succeed, the capability for follow-up of all vulnerable children and families is crucial. Furthermore, since many youngsters and families will present needs (eg, child care, parent education and support) which do not require the intensity of an early intervention program, linkages must be formed with a broad array of community based resources and agencies. Methods for developing the most effective processes for such linkage must also be addressed in the future.

Finally, while the merits of early identification and intervention are irrefutable, the feasibility of large scale, population based responses has yet to be verified. Studies which assess the intrusiveness of such procedures are critical, not only from the perspective of the most effective means of gathering information about family needs and strengths, but also in identifying the impact of such screening activities on the time, motion, and cost to the physicians.

Clearly, there is an ever increasing body of literature which verifies the enormous and irreversible effects of early childhood experiences. P.L. 99-457 (Part H) created the opportunity to develop coordinated, in-

tegrated services for infants and toddlers, and moreover, has provided a broad window of opportunity to launch programs which prevent adverse health, educational, and social/emotional outcomes in children. Physicians constitute a major component in solutions which will be generated nationally, and the forthcoming decade will reveal the manner in which the medical community elects to capitalize upon this opportunity.

Summary

Research conducted over the past decade with infants and preschool children has confirmed the positive outcomes of early intervention. As a result, an urgent need now exists to develop strategies which accurately identify children in need of such services. Information derived from a comprehensive research base suggests that developmental surveillance models hold the most promise for accurately identifying developmentally disabled and vulnerable young children; and moreover, that physicians must assume a critical role in such models. Research also indicates that if such models are to be effective, they must be multivariate, child and family focused, and undertaken more than once.

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Traditions and Innovations: A Community-Based Approach to Substance Abuse Prevention

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... Indian Health Service officials have currently defined alcohol, substance abuse, and the diseases associated with alcohol, as the most significant health problem affecting Indian communities.

Introduction

Alcohol and drug abuse among adolescents is a major problem facing American society today. Substance abuse has also been causally linked with other societal problems, including the early age of school dropouts and learning disorders in school. Alcohol and drug abuse are generally considered to be preventable. The present article describes one community's approach to buffering young people against alcohol and drug abuse.

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The community described in this article is a population of Native Americans* located in an urban setting in the northeastern United States. The history and circumstances of Native American populations with respect to alcohol and drug abuse have been the subject of much discussion. Whether causes of alcohol and drug abuse are due largely to historical, socio-economic, or biological factors,^{1,2,3} it is sufficient to know that Indian Health Service officials have currently defined alcohol, substance abuse, and the diseases associated with alcohol, as the most significant health problem affecting Indian communities.⁴ Surveys conducted at the tribal level show that American Indian youth have frequently begun alcohol, marijuana, and inhalant use by age 11 or 12.⁵ Many of

**"Native American", "American Indian", "Native", and "Indian" are used interchangeably throughout this text.*

these adolescents indicate in anonymous surveys that they go beyond casual experimentation to multiple or heavy drug use, a fact reflected in the estimate that nearly one-half of all American Indian adolescents are at risk for physical and emotional problems due to alcohol and drug use.⁶ Researchers have worked to identify the specific prevention needs of Native American populations, including culturally sensitive approaches to building self-esteem.⁷

The RIIC Peer Assistants Program

In 1987 the executive staff of the Rhode Island Indian Council began plans to implement a sub-

ABBREVIATIONS USED:
CHARLIE: Chemical Abuse Resolution Lies in Education
RIIC: Rhode Island Indian Council

stance abuse prevention program. A needs-assessment survey conducted by the Council in 1980 estimated the Native American population in Rhode Island to consist of 4,000 individuals from over 50 tribes, although informal estimates suggest that the actual population in the state is higher. The survey also found the rate of unemployment and underemployment among the American Indians in the state was nearly three times that of the general population, and that nearly half of the American Indian population did not finish high school or receive a high school equivalency degree. The Council operates many different programs to help this population, including job training and placement, education for youth, housing, health education, a communication network, family violence prevention and other social services, and a cultural education program. A major theme of these programs, dating to the founding of the Council in 1975, involves providing a cultural base and a sense of community—a "stronger sense of self-esteem and pride in the Indian heritage" for individuals and families that live apart from their tribes.⁸

The children participating in the substance abuse prevention program are all between the ages of 7-13, with older children and adolescents between the ages of 14-19 serving as peer assistants to the prevention program. All are children of American Indian descent. Some have parents from areas throughout the United States who are currently living in Rhode Island, while others are members of the Narragansett Indian Tribe. When approaching the Narragansett and other Indian tribes located in the north-

eastern United States, it is helpful to understand the long history of warfare, decimation, forced relocation, and discrimination faced by these peoples. By the late 1600s a stereotype of American Indians as being particularly prone to drunkenness and indolence already was widespread throughout the British colonies of southern New England, and those surviving American Indians were repeatedly prosecuted for drunkenness and related behaviors.⁹ In a recent series of newspaper articles, Gaines documented the experiences of several New England Indian tribes, including the Narragansetts, in the struggle to regain some sense of Indian identity. White has noted the popular non-Indian misconception that "true" American Indians can be found only west of the Mississippi River. The appearance of many eastern American Indians, and the fact that many groups have grown up considering tradition to be items of the past, are principal complications in the search for Indian identity.¹¹

The Narragansett Indian Tribe received renewed federal recognition in 1983. The history of the Narragansett, including the depopulation and the lack of federal recognition, has tended to heightened the conditions described by White¹¹ and to interfere with the exploration of Indian identity. For many young people of the tribe, involvement with or information about their Indian heritage is new. Many youths in the urban area express concerns over the legitimacy of their connections with an American Indian past, and while they want to learn more about "what it means to be Indian", they sometimes ask themselves

whether they have any right to think of themselves as "real Indians".

Theoretical orientation

This program utilizes a basic prevention curriculum and model that provides drug-specific information, affective education, the development of individual social competencies, and the promotion of healthy alternatives to chemical use.¹² Prevention programs in many Native American communities follow a varied approach of addressing existing knowledge, attitudes, and behavior. In addition, many of these programs are individualized to incorporate the additional element of cultural traditions for younger members of the community.

The Red Cliff program, conducted with over 1,000 school children in Minnesota, Wisconsin, and Michigan school systems, used traditional Ojibwa legends and teachings to present a cultural perspective on wellness.¹³ Similarly, in White's program among the Lumbee in urban Baltimore, thirty-two Lumbee youth participated in learning about and creating traditional art, as well as in helping to clean up a community and perform community service work.¹¹ The rationale for these programs is readily understandable and is consistent with the attitudes and values of Native American communities, where it is often stated that young people must develop an inner strength based on their heritage in order to be successful in the modern world.

Academic research has also supported incorporating cultural traditions into prevention programs for children. In an important study, Mason demon-

strated a significant relationship between American Indian children's self-concept and their likelihood of using alcohol and drugs, and provided empirical evidence for the role of cultural teachings in prevention programs by showing that low drug use correlated, for example, with enjoyment of participation in tribal activities and customs. Mason suggested that self-concept among American Indian adolescents is primarily culturally-oriented, and that a positive self-concept is negatively correlated with alcohol and drug use.¹⁴ The RIIC Peer Assistants program was based in large part on Mason's findings.

Activities of the program

The prevention curriculum used in this program was built around a core program known as "Project CHARLIE" (CHemical Abuse Resolution Lies In Education), which was designed and implemented in the Edina, Minnesota school system and has since been used in many other parts of the country. Project CHARLIE was cited by the Indian Health Service in 1987 as one of the four most widely used prevention programs among American Indian populations, in part because it is designed principally to target self-esteem and is readily adaptable to different cultural groups. The Project CHARLIE curriculum is organized into four major units that help children to avoid involvement with alcohol and drugs: self-awareness, relationships, decision-making skills, and chemical use in society. Each unit is composed of a number of different lessons and contains numerous suggestions for projects and activities.

In addition to this core pre-

vention curriculum, the Rhode Island Indian Council program includes a focused component in the area of cultural awareness. The adolescents and younger children participate in cultural activities that include learning American Indian handicrafts native to the Northeast and other regions, such as beadwork and moccasin making, listening to traditional songs and lore, and learning about traditional subsistence patterns and the prehistory of the region. Beyond a simple involvement in the activities, participants are encouraged to explore their own identity as American Indians through the designs they create (in beadwork, on t-shirts, etc.), the stories and poems they write, the paintings they do, and through such creative mediums as writing a puppet show, doing a coloring book to teach younger kids about the dangers of drug use, making colorful anti-drug use posters, and producing videotapes that can be sent to other groups who are developing community-based prevention programs. Trips to museums, powwows, and historical sites of importance to the heritage of the young people generate many discussions of current events and of personal values and attitudes.

To date, the program has been running for over two years, and more than 75 children have participated.

Program outcome data

Prevention programs are difficult to evaluate. Community members often do not see the need for evaluations and self-report data are called into question.¹⁵ For these reasons, and because standard evaluation tools may not be sensitive

enough to record actual changes in special populations, the pilot phase of the Rhode Island Indian Council program employed an evaluation strategy that included both standardized instruments and ethnographic interviews and observations. This evaluation package included an alcohol and drug use survey to collect self-report data on quantity and frequency of alcohol and other drug use, as well as reasons for using drugs, a standardized test of self-esteem,¹⁶ and a semi-structured interview about the role and importance of cultural elements to the individual.¹⁴ This interview addressed such questions as knowledge of family or group traditions and participation in community activities.

Results

The value of teaching cultural traditions as part of a substance abuse prevention program may be seen in a number of outcomes of the pilot study, as well as in data collected throughout the remainder of the program.

Two groups of adolescents were involved in the initial pilot study, totalling thirty-four subjects (the study is described in more detail in reference 17). Each youth was involved in the study through participation in a 25 hour-power-week summer employment program. Nine individuals, aged 14 to 19, participated in the Indian Council prevention program. This program served as the major test of the hypothesis that the teaching of cultural traditions prevents alcohol and drug abuse. In addition, a non-equivalent comparison group of 25 individuals, aged 14 to 18, was selected from among adolescents in another summer employment program.

This group, which included many Hispanics and Blacks, met the same income level criteria (to qualify for federal assistance programs) and lived within the same residential area. A non-Indian control group that was equivalent in socio-economic factors, urban residence patterns, and inclusion in a similar summer program was also selected.

Initial indicators in the pilot study include participation for the duration of the program, changed scores on the cultural affiliation, self-esteem, and drug use inventories from the pre- to post-program administration, and behaviors related to presentation of self and life choices. For example, in the pilot study, eleven out of the twenty-five individuals in the comparison group did not complete the program, while all of the individuals in the Rhode Island Indian Council group completed the program. Those individuals in the comparison group who reported the greatest involvement with alcohol and drugs did not complete the program, while test group individuals who reported a similar level of involvement with alcohol and drugs did remain for the entire length of the prevention program. Additionally, data indicated a reduced rate of alcohol and other drug use in the group that included teachings of cultural traditions. The data indicated both a significant reduction of drug use between the two groups, and a significant correlation between increased cultural affiliation and decreased alcohol and drug use. No significant correlation was found between changes in self-esteem and changes in alcohol and drug use.

There are other indications

of the importance of the program. Older adolescents continue to report the importance of teaching younger children how to avoid the dangers associated with alcohol and drug use. Parents are now invited in regularly to see their children's progress, and in several cases this has led to reduced tensions within families. Children who were having trouble in school find that being part of a community program helps them to do better at school.

Summary

We know from the various data gathered in this study that the cultural material presented in the program was well received and contributed to reducing alcohol and drug use among American Indian adolescents. Individuals also reported enjoying these activities, statements which are important in light of the need to generate and maintain interest in a community-based prevention program. Yet, the specific mechanism by which making moccasins, visiting reservations, or participating in pow-wows serves to decrease drug and alcohol use is still to be discovered. Is there a cognitive mechanism or thought process at play – do individuals actually think "Now that I can do this, I don't want to do drugs anymore"? Or do intervening variables mediate between increased cultural affiliation and the decision to change alcohol and other drug use behavior.

Although further investigation of the specific mechanism connecting cultural traditions and decreased drug use is beyond the scope of this article, some additional observations may shed light on the subject. When questioned, many of the

older participants in this study remembered having some kind of drug education program in school, but they described these as simply another aspect of the educational process. These educational programs were represented as a place to learn somebody else's views and decisions, which then could be added to a general fund of knowledge. Individuals had not fully adopted these teachings as part of their own decision-making process about alcohol and other drug use. For a prevention program to be successful, it seems likely that it must affect individuals strongly enough to influence and support decisions that go against the dictates of the peer group and other social elements that promote alcohol and drug use. The program must also provide a feeling of being in control, of being in a safe setting, and of being able, at least to some extent, to shape their own future.

... data indicated a reduced rate of alcohol and other drug use in the group that included teachings of cultural traditions.

Insight into one important mechanism was provided through discussions with adolescents about the possibility that they begin to teach the prevention curriculum to younger children. In a television interview conducted at the end of the program, several American Indian youth reported that the aspect of the program they liked best was "being able to help little kids", and that they had previously thought that they "would be doing nothing after school, but now would be helping little kids not to use

drugs". Concern was repeatedly expressed over what was perceived as an increasing use of drugs by younger children who were too innocent and unprotected to resist the lure of alcohol and other drug use.

... prevention lessons can affect actual choices about chemical and drug use if a transformation occurs in the individual's perception of being the prevention provider, rather than solely a target of the prevention effort.

The findings of this study suggest that prevention lessons can affect actual choices about alcohol and drug use if a transformation occurs in the individual's perception of being the prevention provider, rather than solely a target of the prevention effort. The use of older children to help in prevention efforts is not a new concept in the field of prevention but the most important finding here is that (at least in a high-risk population, where individuals perceive themselves as outside of or unsuccessful in mainstream society), a real transformation must occur for individuals to believe themselves capable of being influential in the prevention program. A heightened sense of cultural affiliation leads to a heightened sense of responsibility to one's community, and the children who have participated in the Rhode Island Indian Council program like this heightened sense of responsibility. It makes them feel important, and provides a new avenue for gaining positive recognition and reinforcement.

One of the important components in drug abuse prevention

efforts, therefore, is that element or combination of elements which allows individuals to perceive themselves as sufficiently "transformed" to become a part of the solution to the problem. The Program Coordinator of the Indian Council program related an observation that provides insight into one such transformation: When many of the children first come into the program, they refer to Indians as "they". However, after being in the program and learning about their heritage, they speak of Indians as "we". In the case of Native American groups, teachings of material, oral, and other cultural traditions can serve as an important component that provides children with the necessary buffers against alcohol and other drug abuse.

Conclusions

Outcomes of this program support the teaching of cultural heritage in order to provide adolescents with a viable means to develop a different role in their community, thereby helping to prevent their own abuse of alcohol and drugs. With a core prevention program that provides information and teaches self-awareness and skills, cultural elements can be used to strengthen bonds and allow access to health-promoting values and norms of the larger society. When this program is individualized by a community to include elements specific to their population, the individual can integrate these teachings into a self-image as a successful cultural group member, as well as a well-integrated individual. It is hoped that these processes of change are sufficiently generalizable, regardless of the specific content preferred by a commu-

nity or cultural group, to allow this approach to be personalized and used with other American Indian and minority groups.

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Indications: Yocon[®] is indicated as a sympatholytic and mydriatic. It may have activity as an aphrodisiac.

Contraindications: Renal diseases, and patient's sensitive to the drug. In view of the limited and inadequate information at hand, no precise tabulation can be offered of additional contraindications.

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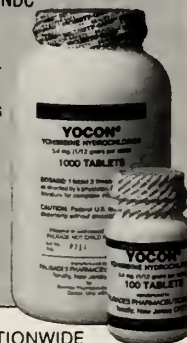
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Childhood Lead Poisoning: A Rhode Island Perspective

Peter Simon, MD, MPH
Amy Zimmerman, MPH, RD

... lead levels as low as 10-15 ug/dl can cause considerable adverse developmental outcomes.

Childhood lead poisoning continues to be a serious national public health problem. Although rarely fatal and increasingly asymptomatic, lead poisoning is a totally preventable cause of impaired learning and school failure. A growing number of research studies have determined that lead levels as low as 10-15 ug/dl can cause considerable adverse developmental outcomes.^{1,2} A recent report by Needleman *et al* indicated that children who had moderately elevated lead levels in early childhood, despite no overt symptoms caused by the initial exposures, exhibited a seven-fold increase in school dropout rates, a six-fold increase

in reading disabilities and a lower final high school rank.² Despite many successful efforts to decrease the average blood lead level in the United States, the problem of childhood lead toxicity continues to become more widespread and complicated.

The Environmental Defense Fund (EDF) recently reported that lead poisoning is one of the nation's most common childhood diseases. EDF estimates that lead poisoning is so endemic in some urban areas such as Providence that 50% or more of the children under the age of six living in such areas have blood levels over 10 ug/dl.³ The Agency for Toxic Substances and Disease Registry (ATSDR) estimates that nationally between three and four million children ages nine months to five years, (and 400,000 fetuses per year) are at risk of adverse health effects due to lead exposure.⁴ Although poor and minority children are disproportionately affected, the problem cuts across all socio-economic strata.

Most children with documented lead toxicity are exposed to lead from its presence in paint. Other contributing factors include lead contaminated soil and dust (originally contaminated by paint), plumbing, gaso-

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ABBREVIATIONS USED:
ATSDR: Agency for Toxic Substances and Disease Registry
CD: Centers for Disease Control
CLPCP: Childhood Lead Poisoning Control Program
DFH: Division of Family Health
EDF: Environmental Defense Fund
FEP: Free erythrocyte protoporphyrin
NECCLPP: New England Consortium of Childhood Lead Poisoning Programs
Pb: Lead
RIDH: Rhode Island Department of Health
SEA: Southeast Asian

line, occupational sources and other miscellaneous sources such as pottery, folk remedies and toys. Although the use of lead-based paint has been banned for domestic use since the 1970s, recent estimates indicate that there are over 40 million US homes which contain lead-based paint, 2 million of which are in deteriorating condition.⁴

Lead Poisoning in Rhode Island Children

Like many others areas in the Northeast, Rhode Island is struggling with problems of inadequate and deteriorating housing. United States Census data indicate that 65% to 80% of housing units in many high risk inner city neighborhoods (and 30% to 40% of all housing) within the state were built before 1940 (Table 1). This significantly contributes to the risk of lead exposure. These risks are compounded by limited access to

health services for many pregnant and parenting women, and children. EDF estimates that 30,624 (50%) of the Providence-Warwick-Pawtucket population, ages six months to five years of age, have blood lead levels that exceed 10 ug/dl and that 10,317 children have blood lead levels exceeding 15 ug/dl³. Data from the Rhode Island Childhood Lead Poisoning Control Program (CLPCP) indicates that in 1989, of the 20,631 Rhode Island children screened (using current Centers for Disease Control threshold recommendations of free erythrocyte protoporphyrin (FEP) \geq 35 ug/dl and a blood lead \geq 25 ug/dl), 689 had positive screening results (3.3%) and 500 were confirmed cases of lead toxicity.

Leaded paint continues to be the major source of contamination for documented cases detected over the past twelve years by Rhode Island's CLPCP. The

majority of these cases resided in Providence (census tracts 2-7,13,14,25,26), Woonsocket (census tracts 179,180,183), Central Falls (census tracts 109,110), Pawtucket (census tracts 155,156), and Newport (census tracts 405,411). Although some of the housing in these neighborhoods is being improved (improper lead abatement of old Victorian homes presents a growing concern in Rhode Island), the majority of stock is old and deteriorating. Tables 1 and 2 illustrate that in the four inner city Providence neighborhoods designated by the CLPCP as "high risk", between 65% and 80% of the housing units were built before 1940, between 35% and 55% of the residential buildings are considered to be in "below average" condition, between 40% and 70% of the population are substantially below the poverty level, and between 68% and 95% of the

Table 1. Income and Housing Status for "High Risk" Providence Neighborhoods

Providence Neighborhoods (Census Tracts)	Families with Income Below Poverty Level (%)	Percent of Persons Below 200% of Poverty	# of Housing Units Available	% of Housing Units Built Before 1940	% of Housing Units Built 1940-1970	% of Housing Units Built After 1970	% of Residential Buildings in "Below Average" Condition
South Providence Census Tracts (CT 4-7) Upper and Lower	40.4	77.1	2332	68.6	22.9	8.5	54%
Elmwood (CT 2-3) (Elmwood and South Elmwood)	28.1	62.8	4477	66.3	26.4	7.3	45%
West End (CT 13-14)	29.3	64.5	6116	71.1	20.8	8.1	55%
Smith Hill (CT 25-26)	10.6	42.0	2788	78.3	15.6	6.1	34%

Data obtained from Neighborhood Statistics Program, U.S. Commerce Department's Census Bureau, Providence, RI (Based on 1980 Census Data)

*Taken from Housing Study for the City of Providence Final Report, Department of Planning and Development, March, 1990.

Table 2. 1989 Neighborhood Racial and Ethnic Composition by Public School Enrollment for "High Risk" Providence Neighborhoods

Providence Neighborhoods (Census Tracts)	Black	White	Spanish	Portuguese	SEA	Other	Total Minority	% Minority
South Providence (CT 4-7) (Upper and Lower)	604	74	352	20	65	39	1000	93.6
Elmwood (CT 2-3)	765	272	966	32	406	47	2215	88.8
West End (CT 13-14)	1005	385	1098	50	815	27	2994	88.6
Smith Hill (CT 25-26)	49	295	162	36	368	18	633	68.2

population are of minority status.⁵ Thus, it is evident that old and deteriorating houses are serving as homes for the majority of the state's poor, and minority, immigrant and refugee populations. Such populations are often the hardest to reach because of both language and/or cultural barriers, making these individuals at even greater risk for being exposed to lead.

Rhode Island has the largest percentage of Southeast Asian (SEA) residents (based on total

state population) in the United States. The state's SEA community is young and rapidly growing. Prior to 1979 there were fewer than 1,000 SEA refugees in the State. Since then Rhode Island has become the home of approximately 14,000 SEAs (Table 3). At present, 78% of the SEAs live in the inner city neighborhoods of Providence. The remaining percentage live primarily in the dilapidated neighborhoods of Woonsocket.

Results of a follow up study

undertaken in 1987 indicated that the SEA child population experienced an exceptionally high prevalence of abnormal lead screening results (11.8%) when compared to non-SEA children (mostly black and Hispanic) living in the same high risk neighborhoods (3.9%) (Table 4). In addition the SEAs did not experience the same decrease in abnormal lead screening results as seen in other minority groups from 1984 to 1987.

Table 3. Southeast Asian (SEA) Population in Rhode Island 1982-1986 by Origin of Birth

	1982	1983	1984	1985	1986
Cambodian	2500 (42%)	3000 (49%)	2800 (43%)	4653 (49%)	6600 (48%)
Hmong	2500 (42%)	1800 (30%)	2500 (38%)	2813 (29%)	2317 (17%)
Laotian	600 (10%)	1000 (16%)	900 (14%)	1552 (16%)	4300 (31%)
Vietnamese	300 (6%)	330 (5%)	300 (5%)	582 (6%)	500 (4%)
TOTAL SEA	5900 (100%)	6130 (100%)	6500 (100%)	9700 (100%)	13,717 (100%)

*Obtained from Southeast Asian Refugee Project, Center for Disease Control Rhode Island Department of Health

Table 4. Estimated Prevalence of Childhood Lead Toxicity, Providence, RI 1988, for Southeast Asians and Other Non-Whites

Ethnicity	Prevalence of Abnormal Screening* (%)	True Positive Rate** (%)	Prevalence Lead Toxicity (%)
SEA	11.8	50.8	6.0
Non-SEA, Non-White	3.9	60.3	2.3

* FEP \geq 35 ug/m% and Pb \geq 25 ug/m% by fingerstick samples

** Venous blood Pb \geq 25 ug/m%

Additional analysis of the records of cases of confirmed lead poisoning admitted to the lead clinic indicated that although the predictive value of an abnormal screening test in SEAs was lower than for other ethnic groups due to their high prevalence of chronic parasitic infection and iron deficiency anemia, SEAs were almost three times more likely to have confirmed lead poisoning than other minority children living in the same census tracts in high risk neighborhoods in Providence (Tables 4 and 5).

In addition to the SEA community, Rhode Island has a rapidly growing Hispanic population. Rhode Island's Department of Education indicates a 100% increase in the Hispanic enrollment rate over the past five years (Table 6). The Hispanic community is concentrated in Providence, Central Falls, and Pawtucket, as are many other

local immigrant groups (Portuguese, Cape Verdean, Haitian, Colombian, and Nigerian).

Along with the diversity and heterogeneity that constitutes the Rhode Island population come unique problems and challenges. The ethnic groups which live in high risk neighborhoods have a variety of different cultural beliefs, practices and languages. For these reasons, identifying and treating children from these population groups is often time consuming.

Childhood Lead Poisoning Control Efforts in Rhode Island

The Rhode Island Department of Health's (RIDH) Division of Epidemiology (now called Disease Control) created the CLPCP in 1977. The program was initially implemented to coordinate lead screening activities for children under the age of six and to educate health care provid-

ers as to the importance of screening. Categorical grant funds provided by CDC, along with state dollars, were used to support program activities from 1977 to 1982. In 1982 when consolidated block grants replaced categorical funding (Omnibus Reconciliation Act of 1981), RIDH maintained its lead poisoning prevention activities and allocated Maternal and Child Health Block Grant dollars to the Division of Disease Control to continue funding this program. Eventually, in 1987, the CLPCP was transferred to the Division of Family Health (DFH) where it could more appropriately be administered.

Currently in its thirteenth year of operation, the CLPCP utilizes much of the original methodology developed under the guidance of the CDC. Placing emphasis on lead screening and treatment services, the program's productivity has continued to grow. Working with an ever widening network of Rhode Island pediatricians, family practitioners, community-based neighborhood health centers, day care providers and early childhood education programs, the CLPCP has successfully tripled its screening volume from 6,044 screened in 1977 to 20,631 screened in 1989 (Figure 1), and has decreased the state's screening positivity rate (percent positive) from 7.5% in 1977 to 3.3% in 1989. The CLPCP has also been extremely effective in educating private practitioners about lead poisoning. This is evidenced by the increase in the number of screenings generated by private physicians. As illustrated in Figure 1, since 1978 the volume of screenings generated by the private sector has increased 530%, from 1,448 in 1978

Table 5. Confirmatory Lead (Venous Blood) Levels for Providence Children Ages 1-6 Years by Ethnicity (July, 1987 through June, 1988)

Ethnicity	Venous Blood Lead (ugm%)		
	# Confirmed	Pb > 25 ugm%	%
SEA all	59	30	50.8
Cambodian	34	13	38.2
Hmong	21	14	66.7
Laotian	4	3	75.0
Non SEA; Non White	131	79	60.3
Black	72	46	63.9
Hispanic	38	22	57.9
Other	21	11	52.4
White	57	25	43.9
Total	247	134	54.3

Table 6. Number and Proportion of Total Enrollment for Nonwhite Population in Providence City Public Schools 1982-1986

	Asian/Pacific Islander		Hispanic		Black		Total Nonwhite	
	n	%	n	%	n	%	n	%
1982	1451	8.0	2237	12.0	4598	25.5	8286	45.5
1983	1455	8.0	2424	13.0	4713	26.0	8592	47.0
1984	1594	8.6	2892	15.6	4780	26.0	9266	50.2
1985	1842	9.7	3309	17.0	4823	25.0	9974	52.0
1986	2170	11.0	3704	18.0	4920	25.0	10,794	54.0

to 7,665 in 1988. Thus the CLPCP has become a well known public health program which has established a strong working relationship with the private pediatricians and family practitioners in the state. The program is also well known regionally as

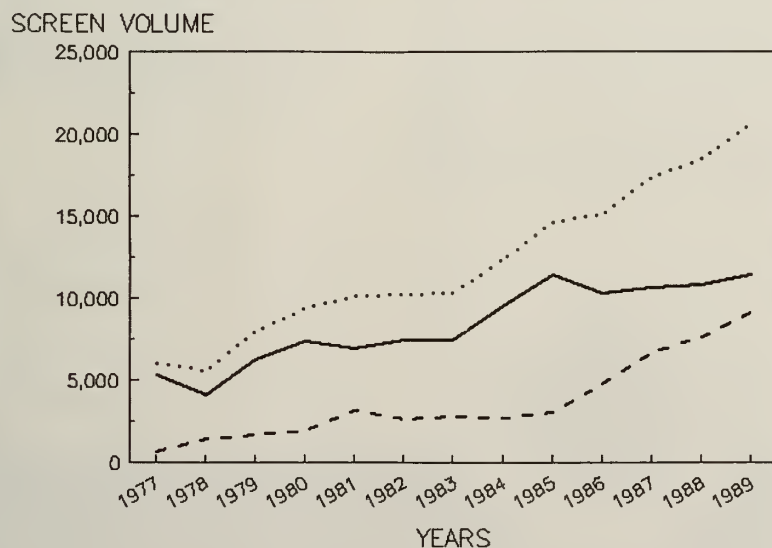
well as nationally. This has resulted from its leadership role in establishing the New England Consortium of Childhood Lead Poisoning Prevention Programs (NECCLPP, a regional consortium to assist New England States in the planning, manage-

ment and evaluation of childhood lead poisoning prevention activities).

Moreover, the CLPCP continues to be successful in providing medical and case management services to a majority of children referred to the state funded lead clinic for treatment and follow-up. A recent series of case reviews dating back to 1987 indicated that only 80 patients (out of approximately 800 new clinic cases since 1987) have been completely lost to follow up.

Despite considerable reductions in its financial and staff support the CLPCP has been maintained. This has been accomplished by having committed individuals review program activities, redefine program priorities and develop realistic plans which would allow the CLPCP to treat those children at greatest risk. Protocols for diagnostic confirmation, environmental investigation, pediatric management, program monitoring and community education were revised with priority given to meeting the needs of younger (nine months to three years of age) lead poisoned children with Class III or IV screening results.

Figure 1. Childhood Lead Poisoning



Public Provider —————
 Private Provider - - - - -
 All Providers •••••

Summary

The Rhode Island Department of Health recognizes lead exposure as the State's most important environmental health problem. Historically, the program has relied on secondary prevention strategies consisting primarily of screening, case-finding, limited environmental intervention and medical management. While secondary prevention of lead toxicity identifies existing cases in a preclinical stage, it does not prevent exposure to lead hazards. The sources of lead exposure need to be appropriately identified and abated if exposures and re-exposures are to be prevented. Because of the ubiquity of lead and practical limitations of available resources, a large number of children with elevated blood lead levels will continue to go unscreened and undetected unless more effective screening strategies are implemented. Present reliance on the free erythrocyte protoporphyrin (FEP) test as a primary screening tool is recognized as an insensitive way to

identify children with blood lead levels below 40 micrograms %. With growing evidence of toxicity and long term health effects associated with blood lead levels in the range between 10 and 40 micrograms %, blood lead analysis will need to become part of the routine method of screening.

Because of the ubiquity of lead . . . a large number of children will continue to go unscreened and undetected unless more effective screening strategies are implemented.

With additional resources, Rhode Island's CLPCP could efficiently and effectively create a strong environmental primary prevention program. Financial assistance from the CDC will provide the RIDH with the resources needed to implement a comprehensive environmental lead risk assessment and reduction program while simultaneously altering and expanding existing screening strategies.

Implementation of these two strategies will reduce the incidence of lead toxicity among Rhode Island's childhood population.

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Aging 2000: Pursuing Progressive Care for Rhode Island's Elderly

Ira C. Magaziner

... our state ranks first in the US in the proportion of its population over 85 years of age.

For the past year and a half, an ad hoc committee has been meeting under the sponsorship of the Interfaith Health Care Ministries with the goal of improving the health care system for Rhode Island's elderly population. Comprised of more than 150 nurses, consumer advocates, physicians, health care regulators, nursing home administrators, government officials, medical ethicists, third party insurers, lawyers, community workers, clergy, academics and other concerned caregivers, consumers and providers, the aim of the committee is to pursue new and progressive approaches to enhanced elderly care.

The name of the project is Aging 2000.

Elderly care is an especially

important issue for Rhode Island, since our state ranks third in the nation in the proportion of total population who are elderly (over 65) and first in the US in the proportion of its population over 85 years of age.¹

Working with the Aging 2000 committee is a staff of 10 individuals with a variety of skills, including researchers, social scientists, health care professionals, business strategy consultants, cost analysts, and public policy activists.

The committee met monthly and the staff conducted interviews and researched elderly care systems locally, nationally and internationally. The Aging 2000 staff conducted nearly 1,000 interviews with health care professionals, consumers and providers in Rhode Island, as well as hundreds more in twelve states and five other countries.

Staff members visited nursing homes and hospitals to talk with patients and administrators. They rode on transportation vans with the elderly, and talked to rescue vehicle drivers

in their stations. They went into doctor's offices to see physicians, nurses, and bookkeepers. They visited senior centers, ate at meal sites, and met with shut-ins in their homes. They accompanied visiting nurses on their rounds and observed numerous shifts in hospital emergency rooms, intensive care units, medical floors, and operating rooms. They attended conferences, seminars, and meetings.

In addition to these interviews, the staff traced the flow of dollars in order to better understand the complex channels of payment and reimbursement. The staff analyzed the time spent by doctors, nurses and nurses' aides in hospitals, nursing homes and physicians' offices for hundreds of hours, while conducting a detailed strategic cost analysis of the elderly health care system which has no precedent in Rhode Island.

After a year of study and a series of meetings with the entire committee, and armed with growing amounts of research,

Ira C. Magaziner is president of SJS, Inc., a public policy consulting firm in Providence. An international business strategy consultant, Mr. Magaziner serves as a director of Aging 2000.

smaller, more intense, focus groups were convened to attempt to pinpoint the major problems affecting elderly health care in Rhode Island. Committee members were presented with a simple, but challenging premise: given a blank sheet of paper, disregarding current restrictions, how would they design an ideal system for elderly care?

The Aging 2000 staff conducted nearly 1,000 interviews with health care professionals, consumers and providers in Rhode Island, as well as hundreds in twelve states and five other countries.

Those who had entered the process on what seemed like opposite sides of the fence soon stood together in their views of how to improve the elderly care system.

Building From Scratch

Aging 2000 members are convinced that applying band-aids to the current system's ills will not be enough. Such incremental stopgap measures have in fact contributed to the chaos of the current system. They realize that lasting improvements will require systemic rather than piecemeal changes. Rather than remodelling our current structure, we can build another from scratch. We'll use the bricks that proved effective in the original system, put aside those that failed, and will add new bricks – innovative measures which will help strengthen an improved model.

Aging 2000 committee members, despite their disparate interests, backgrounds, and expe-

rience agreed on the key problems that need to be addressed.

1) The system is too bureaucratic, with too many complex regulations and reporting requirements for care providers, and too many confusing and complicated rules for consumers and their families.

2) The fragmentation of services makes it difficult for consumers and their families to gain the information and access the need for existing care systems.

3) There is a lack of continuity for consumers who must see dozens of doctors, nurses, test givers, social workers and system administrators in the course of an illness. This can result in poor care, unnecessary testing and lost information.

4) It is often difficult for people wishing to stay in their homes rather than enter hospitals or nursing homes to secure the services that would allow them to do so.

5) People must often switch their place of residence as they age and find it a difficult and anxious transition.

6) Decisions relating to the effectiveness of medical procedures on very ill, frail elderly patients are often made in a haphazard fashion with inadequate ethical guidelines.

7) Very few doctors, nurses, social workers and managers are educated to the specific needs of the elderly.

8) Elderly people are often taking multiple medications prescribed by different doctors which can produce adverse reactions; people are often confused about their prescription dosage; and medications are too expensive for many.

9) The elderly health care system is very expensive for the value received. We are spend-

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ing over \$4,500 per year of public funds for every elderly citizen in Rhode Island and yet many are dissatisfied and some receive inadequate care.

Turning Ideas into Action

The entire committee and staff met for two days on February 1 and 2 to try to reach consensus on models to address these problems, and how to implement them in Rhode Island. The Aging 2000 agenda was forged from these intensive meetings.

The Aging 2000 report will be issued this spring, 1991. It will provide a thorough analysis of Rhode Island's elderly care system, describe problems, and make recommendations for new, comprehensive approaches to solving these problems.

Models of innovative elderly care will be created in Rhode Island within the next few years. Funding schemes to finance these models will be put in place. In upcoming issues of the *Rhode Island Medical Journal*, Aging 2000 will share with readers, through a series of articles, the models that are being considered.

After years of frustration, of seeing the best intentions go awry, watching new ideas fall prey to financial constraints, and hardest of all, having to cope with human pain and suffering while trying to struggle with an enormous bureaucratic system – it is easy to be cynical about the possibilities for improvement. In fact, common sense might tell one that to be anything but skeptical about overhauling the current system is foolish.

But for the past year and a half, more than 150 professionals and lay people – neither cynics nor fools – have led the fight for improved care, battling

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in community centers, nursing homes, adult day care centers, hospitals and their own homes, and have made a commitment to change. They have pooled their talents, resources and experience, and have already begun drawing attention locally and nationally.

Committee members were presented with a simple, but challenging, premise: given a blank sheet of paper, disregarding current restrictions, how would they design an ideal system for elderly care?

Elderly health care issues touch everyone: families, neighbors, clergy, public servants, but none more so than the professionals in the field. Rhode Island can become a model state in elderly health care. It can build a system that is affordable, financially equitable, and one which gives independence and dignity to our older members of society. But we will need to forge a common effort. We welcome the opportunity to seek the participation and support of readers of the *Rhode Island Medical Journal* in our quest.

The new buildings are going to go up. The foundation has already been laid. Everyone is welcome. Bring your own plans and tools. Just come prepared to work.

References

- ¹ Murphy, JB & RA Silliman, "Older Rhode Islanders: Demography, Health Status and the Implications for the Practice of Medicine" *RIMJ* 74 (2):55, 1991.

NINE PROBLEMS IN ELDERLY CARE

Through a grassroots process of consensus-building among the Aging 2000 committee members, the group defined nine key problems that must be conquered in order to provide improved, progressive elderly care for Rhode Island:

1) COMPLEX BUREAUCRACY.

The system is too bureaucratic with too many complex regulations and reporting requirements for care providers, and too many confusing and complicated rules for consumers and their families.

2) FRAGMENTATION OF SERVICES.

It is difficult for consumers and their families to gain the information and access they need to existing care services.

3) LACK OF CONTINUITY.

Consumers must see dozens of doctors, nurses, test givers, social workers and system administrators in the course of an illness. This lack of continuity can result in poor care, expensive testing and lost information.

4) DIFFICULTY IN ACCESSING HOME SERVICES.

People who wish to remain in their homes rather than go to nursing homes or stay in hospitals often find it difficult to secure the services they need to allow them to do so.

5) SWITCHING RESIDENCE.

People must often move their place of residence as they age and find the transition difficult and anxiety-producing.

6) NEED FOR ETHICAL PROTOCOLS.

Decisions relating to the effectiveness of medical procedures on very ill, frail elderly patients are often made in a haphazard fashion with inadequate ethical guidelines.

7) LACK OF KNOWLEDGE OF ELDERLY NEEDS.

Very few doctors, nurses, social workers and managers are educated to the specific needs of the elderly.

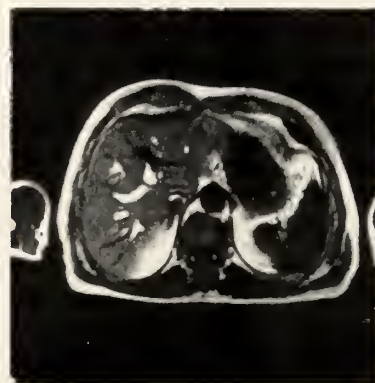
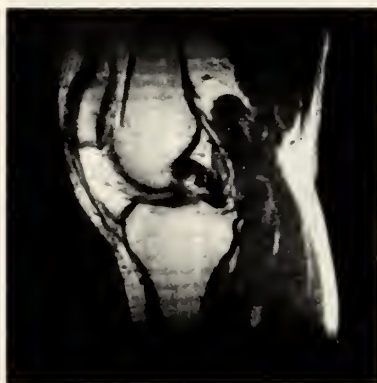
8) PROBLEMS WITH MEDICATIONS.

Elderly people have difficulties with medicines; they are often taking multiple medications prescribed by different doctors which can react adversely with each other; people are confused about the specifics of their prescription; and medications are too expensive for many.

9) EXPENSE OF THE SYSTEM.

The elderly care system is very expensive, costing over \$4,500 per year of public funds for every elderly citizen in Rhode Island.

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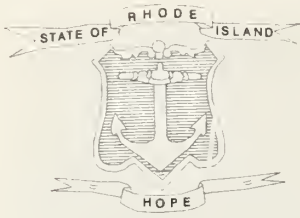


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Low Birth Weight in Rhode Island: The Survival of the Tiniest

The incidence of low birth weight (newborns weighing less than 5 lbs 8 oz, or 2,500 grams) is an important public health indicator because low birth weight (LBW) is the strongest predictor of infant mortality. In the United States the risk of death in the first year of life is 94 times higher for babies who weigh less than 1,500 grams at birth (very low birth weight infants), and thirteen times higher for babies weighing between 1,500 and 2,500 grams, than for those weighing more than 2,500 grams.¹ Very low birth weight (VLBW) infants represent only 1% of births, yet they lead to 40% of infant deaths.²

Figure 1 shows the incidence of low birth weight in Rhode Island for the past ten years. Although there is variation from year to year, there is no real difference between the five-year averages for low birth weight for 1979-83 (6.3%) and for 1984-88 (6.2%). During the period 1984-88, the rate of low birth weight was high among black newborns (12.0%), among babies born to teen mothers (9.4%), and among infants living in poverty areas (9.6%). If all these risk factors are combined, the rate of low birth weight for black teen mothers living in poverty was 14.6% or 2.5 times the state average.

Even though the LBW rate has remained constant, the number of low birth weight babies being born in Rhode Island has increased, because the number of births

has risen. In 1979 there were 789 LBW newborns born in Rhode Island and in 1988 the number rose to 849. The survival rate of low birth weight infants has improved due to the successes of neonatal intensive care.

Most LBW babies now go home healthy, however, low birth weight has been associated with neurodevelopmental problems and is a significant predictor of school failure.³ This is especially true for VLBW infants. It is estimated that 38% of VLBW infants fail in school, as measured by scores on achievement tests.⁴ A follow-up study of 42 VLBW infants born in Rhode Island showed that 54% required special education or resource help at 7 years.⁵

Figure 2 shows the incidence of VLBW in Rhode Island from 1970-1987. The most notable trend is the steady increase of infants being born in the 500-999 gram category. During the 1970s 25% of VLBW infants survived for one year or longer; now the survival rate is 75%.⁶ Applying these estimates to Rhode Island means that of the 147 VLBW infants born in 1979 only 74 survived. In 1988 the same number of VLBW infants were born (n=147) but, it is estimated that 100 of these newborns survived. This represents a 49% increase in this group in ten years.

These improved survival rates mean there are many more infants with special health care needs that enter the health, social service and educational systems in

the state. As these children reach school age the need for special educational services will increase. Even for the VLBW survivors who do not have dramatic physical or developmental problems, more research is needed on their long term health and educational needs in order to determine the total effect on society of the increased survival rates among this group.

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Figure 1.

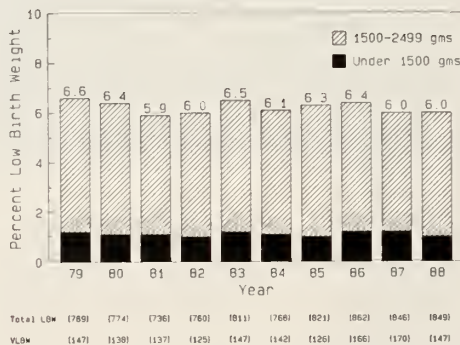
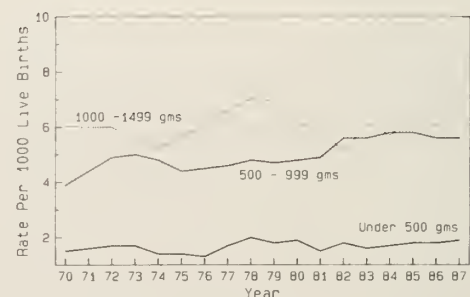


Figure 2.



Submitted by the Division of Family Health, Jane Griffin, MPH and William H. Hollinshead, MD, MPH.. Health by Numbers is edited by Jay S. Buechner, PhD, and William J. Waters, Jr., PhD.

THE RHODE ISLAND MEDICAL JOURNAL

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THE RHODE ISLAND MEDICAL JOURNAL HERITAGE

Ninety Years Ago (April-June, 1901)

An article on nitrous oxide anesthesia in general surgery is authored by Dr Albert H. Miller (16 years later to become editor of the *Rhode Island Medical Journal*.) He states, ". . . We must gladly welcome a method of anesthesia which largely does away with the sensation of choking and suffocation during etherization and the subsequent nausea and vomiting." The various pieces of anesthetic apparatus for delivering both gas and ether, with provision for an adequate flow of oxygen, are carefully described. A review of 160 cases undergoing gas-ether anesthesia shows that the average time to anesthetize is 3.05 minutes, and 84% of these cases suffered no nausea or vomiting. The author concludes: "The combination of nitrous oxide and ether as a general anesthetic has not been equalled in consideration of its safety, saving of time of the surgeon and assistants and as a means of diminishing the measure of suffering of those intrusted to our care."

Dr Donald Churchill writes an

article, "Appendicitis at the Rhode Island Hospital, 1891-1900." The opening paragraph represents a notable departure from the customary style of medical writing by reflecting upon intensely personal experiences. The author begins his year end paper as follows: "If in choosing appendicitis as a subject for my paper tonight, I have seemed to hit upon a theme so trite as to be uninteresting, my reason is that being a victim of that dreaded disease myself, it was directly the cause of my coming to the Rhode Island Hospital now six and one-half years ago. Although I underwent two operations and suffered three of the complications of the disease, my stay here was made so pleasant that I decided to study medicine; and just a month from the day of my discharge I was enrolled in the Harvard Medical School. While in the Medical School, purely by chance, I was given as a subject for my surgical thesis, a case of appendicitis." Churchill proceeds to describe the age distribution, gender and outcomes of 269 cases of acute or chronic appendicitis. He notes that most

(78.5%) are males and that the average age is between 20 and 25 years, the oldest, 58 years of age. Post-operative mortality was 22.5%. The commonest post-operative complications were fecal fistula, deep abscess and stitch abscess. He concludes, "The country physician and general practitioner have, thanks to a voluminous amount of literature and perhaps a few bitter experiences, learned to send for a surgeon at the first alarm and make him share the responsibility. The surgeon, more and more progressive, thoughtful and experienced, is operating earlier and earlier. Ten years hence I firmly believe that our mortality will be certainly not more than half the present rate, and perhaps even less, for it has been clearly proven that appendicitis is a surgical disease, and surgeons of large experience have come to the conclusion that in the long run they will save more lives by operating on all cases, with very few exception, as soon as the diagnosis is accepted."

Dr G.A. Matson presents a case of lachrymal sac sarcoma in a 12-year-old boy. The tumor

presented as a large malar mass. Under cocaine anesthesia a fragment was excised for histological diagnosis and was declared to be a round cell sarcoma. Six weeks following major resection, the mass reappeared. The child died about three months later.

Fifty Years Ago (June, 1941)

The lead article by Dr L.C. Kingman is entitled, "A Generation of Surgery." The paper is a distillation of the Presidential address before the Rhode Island Medical Society and reflects upon the vast changes in the practice of surgery during the speaker's 35 years of professional experience. He asks, "Wherein lies the difference between a gall-bladder operation of 1905 and 1941?" This is an article rich in reflection and historic insight. A few, isolated quotations follow: "Anatomy, I think, was better known by the surgeon then than now." But, "There has been a gradual increase in the scientific point of view, going from the general to the particular instead of the reverse, more proper evaluation of statistics, observations to find the truth not to prove a theory or assumption." "In the art of practice, the handling of patients, we have seen a change I think for the better." As to diagnostic ability, "We make better diagnoses . . . but are we as good diagnosticians? The advance in diagnostic aids—mechanical and laboratory methods—often blunts our powers of observation and deduction." And, of course, "Some of the diseases that we had to combat have nearly disappeared—tuberculosis of

glands, bones and peritoneum, the typhoid perforation, anthrax." And for new adjuvants to surgery, ". . . We have insulin, liver extract, vitamins, novocain, barbiturates, arsenical, and bismuth, chemotherapy, radiation therapy . . ." Finally, the author states, "I am of the belief that this era reviewed has but laid part of the ground work for what will be a most rapid advance in our science and art, both in surgery and medicine."

The issue carries the transcript of a panel discussion on preventive inoculation chaired by Dr H.E. Utter. Other participants include Drs W.P. Buffum and B. Feinberg. Immunization procedures against small-pox, typhoid, tetanus, scarlet fever, diphtheria, measles and whooping cough are described and discussed.

The lead editorial discusses variation in the terminology employed when identifying tumors and advocates a standardized nomenclature based upon the histologic type from which the tumor was derived and the degree of malignancy. A second editorial discusses responsibilities for tuberculosis in Providence. The editorial concludes, "Shameful it is that our elected servants should shirk their responsibility so as to cripple the attack on this plague. If the medical and lay citizens of Providence fully appreciated how much could be done, it is hardly possible that they would stand by silently."

A Clinical Pathological Conference from Rhode Island Hospital is summarized. The case is that of a 63-year-old housewife and the clinical discussions are provided by Drs H.A. Lawson and I.A. Beck. The pathological findings (carcinoma of the gall

bladder) are presented by Dr B.E. Clarke.

Twenty-Five Years Ago (June, 1966)

The lead article by C.M. Moehring and Dr G.F. Meissner describe a tapioca agar-gel electrophoresis procedure of the analysis of abnormal hemoglobins. In summary, the authors state: "A method for the rapid demonstration of the common abnormal hemoglobins and the Hemoglobin A-2 fraction, by Tapioca agar gel (TAG) electrophoresis is presented in detail. The normal values for Hemoglobin A-2 as determined in 124 cases range from 1.09 - 3.5% (average 2.1) . . . In Thalassemia trait the elevated Hemoglobin A-2 ranges from 3.6 - 10.4%. This method results in permanent slides which may be read visually or by means of a densitometer."

W.K. Turner, Director of Newport Hospital, provides the text of a speech describing how the individual hospital can assess its use and costs, employing computer services, to evaluate hospital utilization.

The Presidential Address of Dr W.A. Reid, delivered to the 155th Annual Meeting of the Rhode Island Medical Society is entitled, "The Good Year." The article describes the Society's End Measles Campaign, and organized medicine's public support of PL 89-97 (the Medicare Act). On a closing note, Dr Reid comments that ". . . osteopathy has come a long way since its founding and has lost its aura of cultism. . . . Most members of the osteopathic profession are now taught and practice modern

scientific medicine. This fact should be recognized."

Mrs I.H. Anjoorian describes the various functions and role of the Woman's Auxiliary in the furtherance of sound community health in Rhode Island.

The following officers of the Rhode Island Medical Society are elected: President—H.E. Dannah; Vice-President — M. DiMaio; President-Elect — S.D. Davies; Secretary — S.J. Hoyer; Treasurer — J.A. Dillon.

An editorial discusses the controversial Doctor Draft, and in the light of the armed forces need for physicians (as well as the Berry Plan to permit post-graduate specialty training) comes out in favor of this means of physician-recruitment. Another editorial notes that the year 1966 will see the 300,000th physician serving the American public.

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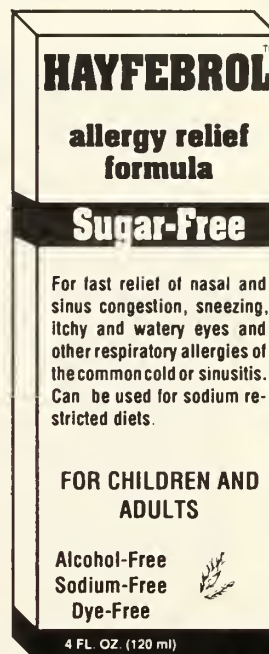
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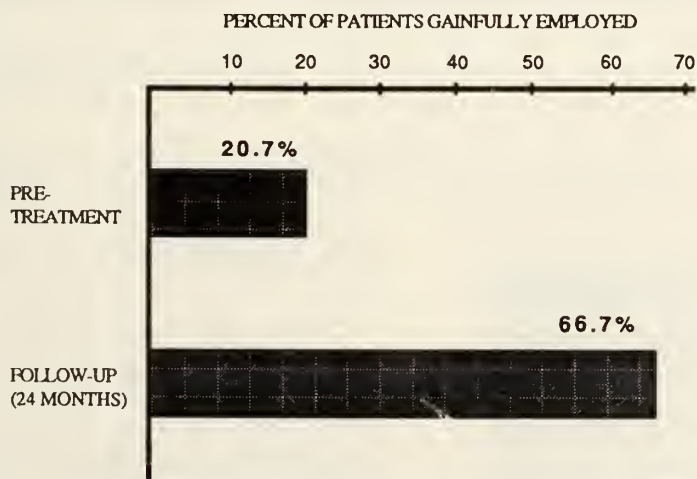
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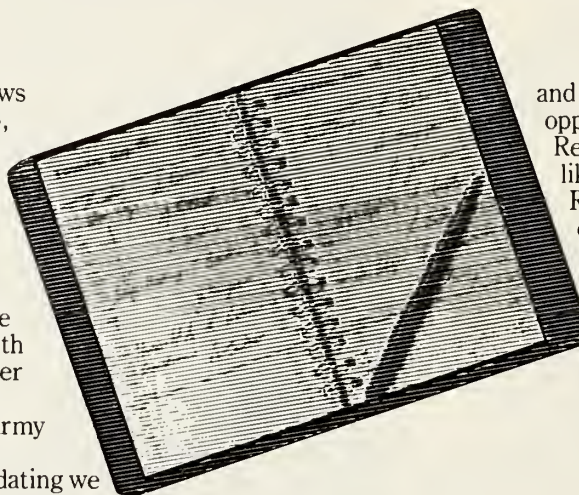
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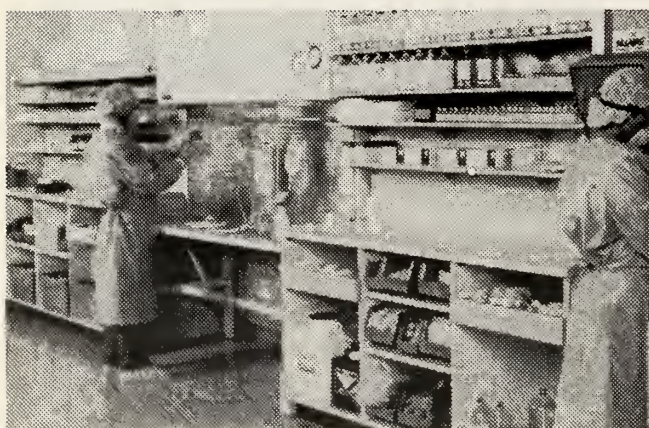
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